



# CALIFORNIA PLAN TO PREVENT AND CONTROL BREAST & CERVICAL CANCER

STRATEGIES FOR CANCER PREVENTION AND CONTROL FOR YEARS 2000-2005

October 2000

A Collaborative Plan Developed by  
The Breast and Cervical Cancer Plan  
Task Force



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BUILDING A FOUNDATION	3
A SNAPSHOT	4
Status of Breast Cancer	4
Status of Cervical Cancer	8
Risk Factors for Female Breast Cancer	11
Risk Factors for Cancer of the Cervix	13
Barriers To Early Detection And Treatment	14
Treatment and Quality of Life	16
GOALS, OBJECTIVES, AND STRATEGIES	17
Criteria for Strategy Development	18
Risk Reduction and Prevention	20
Detection	25
Treatment	33
NEXT STEPS	40
EVALUATION	41
REFERENCES	42
APPENDICES	45
Appendix A: Background of the Plan	46
Appendix B: Key Statewide Resources	52
Appendix C: Task Force Members	56
Appendix D: Expert Reviewers	58
Appendix E: California Breast and Cervical Cancer Advisory Council Members	59
Appendix F: Plan Development Staff and Consultants	60
Appendix G: Key Informant Interviews	61
Appendix H: Summary of Provider and Consumer Focus Groups	63
Appendix I: Summary of CEWAER's Public Forums	74

## BUILDING A FOUNDATION

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Nearly 22,000 women in California—more than 60 per day—will be diagnosed with breast or cervical cancer in 2000. The California Plan to Prevent and Control Breast and Cervical Cancer is intended to reduce the incidence and death from these two cancers. The Plan will facilitate a broad-based, coordinated statewide mobilization of voluntary, private, and public sector cancer control and cancer care efforts that are needed in California over the next five years. It sets a direction for the future investment of public and private resources, and is expected to influence policy, research, and academic agendas.

This is a strategic Plan—not an implementation Plan, or an operational, or an action Plan. Those types of Plans, with defined projects, dollars and timetables, are in the future. This is a conceptual Plan, a framework for action, a vision of the many things that need to be done. A multidisciplinary Task Force spent the better part of a year identifying key issues and developing 124 specific "strategies" for dealing with the two cancers over a five-year period, through a process described in Appendix A. These strategies are the foundations on which action Plans will be built.

Nor is it a "State Plan." Those who developed it recognized the shared challenge of cancer: no single organization alone can improve or change the outlook for cancer. The State will play a role, as will local cities and counties. There are also important parts to be played by community-based organizations, by civic and charitable organizations, by health care systems, and by research centers. Whatever strategies are undertaken, diverse populations should be involved. Ideally, this Plan highlights areas into which various parts of the public and private sector will move.

If one concern stood out during the Task Force's deliberations, it was the lack of funding for detecting and treating breast and cervical cancer. However, for this and for all 124 strategies, the Task Force decided against trying to set priorities for a number of reasons—one of them being that priorities might limit participation by various organizations.

If this Plan is to succeed, it must have the participation and support of the many public and private sector organizations working to prevent or reduce risk and increase detection and treatment of breast and cervical cancer.

*In 2000, about 20,045\* California women will be diagnosed with breast cancer— and about 4,380 will die from it.<sup>1</sup> A disproportionate number of those who die will be older, poor, and non white.*

Breast cancer is the most commonly diagnosed cancer among virtually all women of any race or ethnic group in California. It is second only to lung cancer as a leading cause of cancer-related deaths in women. One in every six cancer-related deaths among California women is due to breast cancer. Although 880,000 low-income California women aged 40 and older who are ineligible for other subsidized services are estimated to be eligible for the State- or federally-funded breast cancer screening and diagnostic programs, resources are available only to serve about 20% of them.

In 2000, about 20,045\* California women will be diagnosed with breast cancer— and about 4,380 will die from it.<sup>1</sup> A disproportionate number of those who die will be older, poor, and non white. Even though research continues to uncover important pieces of the cancer puzzle, there are limited ways to prevent or delay breast cancer. Breast cancer screening, early diagnosis and prompt treatment remain the most effective methods to reduce deaths from breast cancer.

Cancer of the cervix is almost completely preventable. However, approximately 1,760 California women in 2000 are expected to be diagnosed with cervical cancer at a stage that was not detected early when treatment was relatively simple, and 490 women will die from the disease.<sup>2</sup> Racial and ethnic differences also exist in the risk of developing or dying from cervical cancer.

Each case of breast or cervical cancer touches many people. The woman who receives a cancer diagnosis is not the only one whose life is changed forever. The lives of the men, women, and children who love her are also changed. If she survives, they can celebrate their fortune but understand that life is tenuous. If she dies, a mother, daughter, sister, friend, wife, and colleague is lost to a wide circle of people.

## Status of Breast Cancer

### *Female Breast Cancer*

#### *Incidence and mortality*

Breast cancer is the most commonly diagnosed cancer among women of any race or ethnic group in California. One in every six cancer-related deaths among California women is due to breast cancer. The incidence of breast cancer has increased steadily in California and the United States over the last few decades, although most of the increase appears to be associated with increased case detection due to the increased use of screening mammography. Based on data collected by the California Cancer Registry (CCR), which tracks the incidence of cancer in California, approximately 20,045 women in the state will be diagnosed with invasive breast cancer and approximately 4,380 women will die from this disease in 2000.

Rates of death due to breast cancer have remained relatively constant in the United States until about 1990, and have since declined slightly. Breast cancer death rates have decreased 14% in California between 1988 and 1996, the last year for which published data were available. This decrease has only been consistent and

\*The number of breast cancer diagnoses is actually higher when the approximately 3,000 in situ cases (in situ refers to tumors that are confined to the site of origin without invasion of neighboring tissues) estimated by the California Cancer Registry to occur in 2000 added.

## A SNAPSHOT

statistically significant for non-Hispanic white women, however. Even though most breast cancers occur among white women, overall death rates from breast cancer are highest among African American women.

Breast cancer survival is highly dependent on the stage at which the cancer is diagnosed. The five-year relative survival rate is 97% for cancers diagnosed while still confined to the breast compared to 21% for those which have spread to distant parts of the body. A substantially greater proportion of "early" stage diagnoses (in situ and Stage I) was found in non-Hispanic white (61%) and Asian/Other (59%) women than for either Hispanic (50%) or African American (48%) women (Table 1). Breast cancer mortality rates among African American women could in part be due to diagnosis at a later, less treatable stage. Several factors are related to later diagnosis, including lack of access to a regular source of health care and mammography screening services. However, even within cancer stages African American women fare more poorly than white women, indicating that factors other than later detection are involved.

**Table 1**

*Cancer Incidence and Age-Adjusted (1970 US Population) Female Breast Cancer Rates per 100,000 Women by Stage at Diagnosis and Race/Ethnicity, California, 1997.*

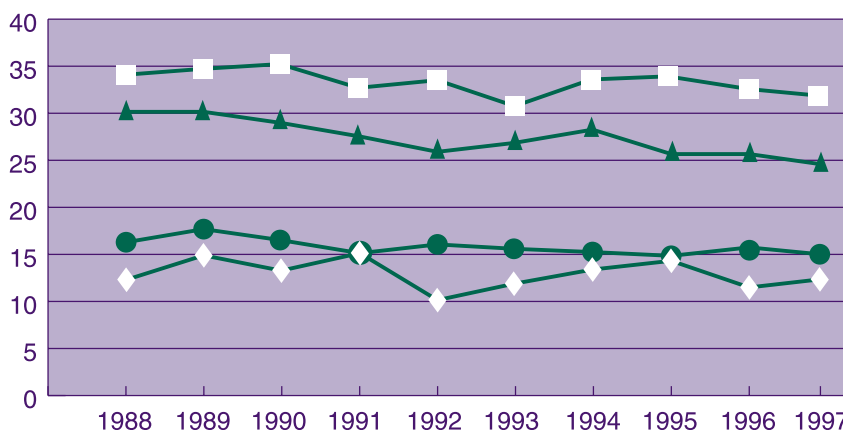
Race/ Ethnicity	In Situ		Stage I		Stage IIa		Stage IIb		Stage III		Stage IV		Unknown Stage	
	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate	Cases	Rate
All Races	3,499	19.8	9,305	51.3	4,738	25.8	2,332	12.7	1,777	6.3	736	4.0	1,279	6.6
Asian/ Pacific Islander	284	14.9	671	36.4	356	18.7	177	9.1	77	4.1	49	2.6	77	4.0
African American	201	18.0	391	35.1	280	24.3	181	15.4	102	9.0	67	5.8	87	7.6
Hispanic	315	10.2	831	27.6	571	17.3	337	9.8	169	5.1	110	3.5	159	4.8
Non- Hispanic White	2,599	22.7	7,332	60.5	3,502	29.1	1,627	13.9	817	6.7	501	4.2	854	6.5

Source: California Cancer Registry. November 1999.

It is difficult to examine long-term trends in mortality by race or ethnicity in California, because death certificates in this state did not consistently identify persons of Hispanic ethnicity until 1985. In general, lower mortality rates among Asian/Other and Hispanic women reflect lower breast cancer incidence rates in these two groups compared to African American and non-Hispanic white women.

Over the 10-year period, 1985-1994, non-Hispanic white women showed a fairly consistent and statistically significant decrease in their breast cancer death rate of about 2.1% per year. Breast cancer death rates among the other three race/ethnic groups showed smaller and less consistent declines, and none of the 10-year trends are statistically significant. However, breast cancer mortality among African American and Hispanic women decreased by about 1% per year on average.<sup>3</sup>

**FIGURE 1 - Breast Cancer Age-Adjusted Mortality Rates in California by Race, Ethnicity and Year**



Source: California Cancer Registry, November 1999.

The decrease in breast cancer mortality in California has not been uniform for all ages. Breast cancer mortality among women less than 60 years old decreased by 25 to 30% over the period 1973-1994, with statistically significant decreases in the age-specific mortality rate of 2 to 4% per year from 1985 to 1994. From 1973 to 1985, the mortality rate among women aged 60 years and older increased somewhat, especially for those 70 to 79 years old. Since 1985, the mortality rate among women 60 to 69 years old has declined by about 20%, with a statistically significant decrease of about 2.5% per year. The mortality rate among women 70-79 years old decreased by 10% and showed a statistically significant downward trend of about 1.5% per year since 1985, while women 80 years old and older are still showing a slight, but not statistically significant, increase in mortality.<sup>4</sup>

### Screening

Breast cancer mammography screening rates have nearly doubled in California over the last 10 years. In 1987, only 38% of California women aged 40 and over reported having had a mammogram in the last two years. According to the California Women's Health survey, by 1997 this figure had increased to 73%, as shown in Figure 2.<sup>5</sup> However, Asian and Hispanic women, less educated women, non English-speaking women, and those reporting a lower income are less likely to have received screening and are therefore at greater risk for being diagnosed with breast cancer at a later stage. Because the data from this survey are self-reported, the actual screening experience is likely to be lower. Studies have shown that screening rates based on patient self-report are markedly higher than rates based on laboratory and medical records. An additional factor in the Women's Health Survey is that populations without telephones and those who spoke neither English nor Spanish were not included.

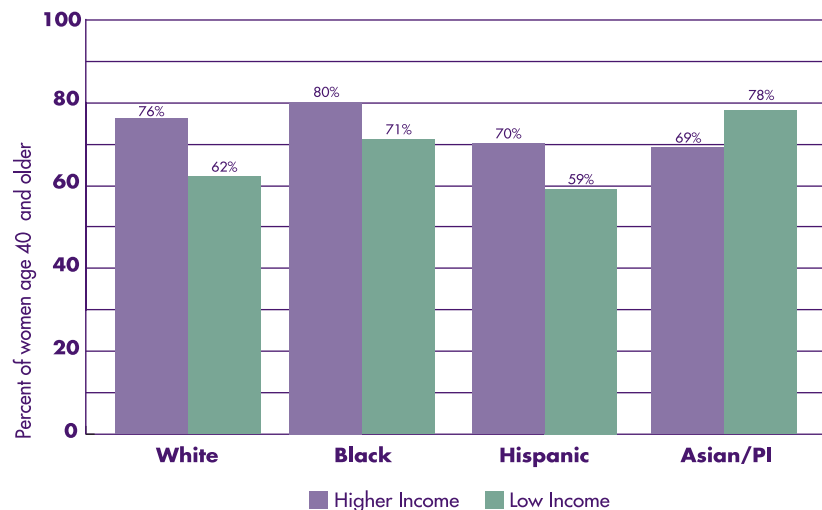
***Breast cancer mammography screening rates have nearly doubled in California over the last 10 years.***



## A SNAPSHOT

FIGURE 2 - Percent of women age 40 and older who had a mammogram within the past 2 years, California 1997

By Race, Ethnicity and Income Status



Source: California Women's Health Survey. California Department of Health Services. 1997.

Breast cancer screening leads to earlier stage at diagnosis of cancer, improved survival rates, and ultimately, reductions in mortality. As much as one-third of deaths from breast cancer among women age 50 and older could be prevented if existing screening technology of mammography and clinical breast examination were fully applied in this population. The range of mortality reduction found in previous trials of regular mammography screening is 19%-30%. A meta-analysis across all age groups showed that mammography reduced the risk of dying from breast cancer by 21%, with most of the benefit seen in women who were aged 50 or older when screening began. Results for women who were aged 40-49 at entry have varied, and the mortality benefits that do occur appear to be delayed, becoming clearly apparent after 8 to 10 years of follow-up.

There is, therefore, continued debate about whether women under age 50 who are not at high risk for breast cancer should receive routine mammography, given that the benefits of reduced mortality may be at the cost of more biopsies and associated anxieties from following up on false positive screening tests. False positive screening results are more common in premenopausal women due to the high density of their breast tissue and lower incidence rate of breast cancer in this age group.<sup>6,7</sup>

Health care providers play a powerful role in motivating women to comply with breast-cancer screening. In fact, research has documented that a physician's recommendation for mammography is the single best predictor of compliance in older women. Women who perceive their physicians to be enthusiastic about mammography are four-and-a-half times more likely to have had a mammogram than women whose physicians show little or no enthusiasm when discussing the procedure.<sup>8</sup> Even when tests are offered free-of-charge or at a low cost, few women seek cancer screening tests without being referred by a health care provider.<sup>9</sup>

*As much as one-third of deaths from breast cancer among women age 50 and older could be prevented if existing screening technology of mammography and clinical breast examination were fully applied in this population.*



### Male Breast Cancer

Breast cancer is rare in men. Among the 182,201 invasive breast cancers diagnosed in men and women during the nine-year period 1988-1997, 0.7% were in men. During the same period of time, 283 California men died from breast cancer (averaging 28 per year), about 0.1% of all male cancer-related deaths.<sup>10</sup>

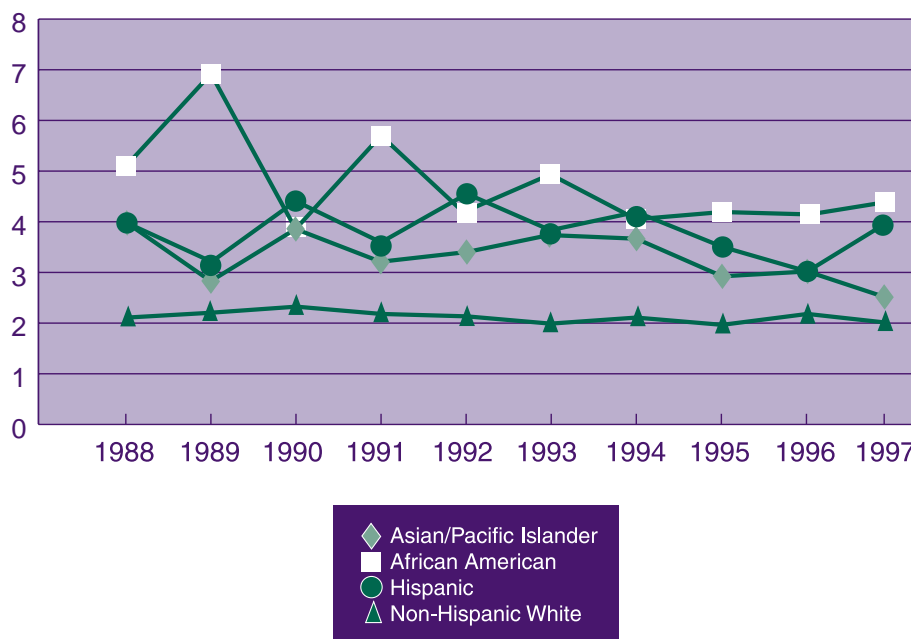
Breast cancer in men is histologically and clinically similar to the disease in women<sup>11</sup>, with the very large difference in incidence being due to the relatively small number of breast cells in men and different hormonal stimuli. Survival is also similar for men and women when matched for age and stage at diagnosis.<sup>12</sup> However, the overall prognosis is poorer because men usually present at a later stage, with a higher frequency of lymph node involvement. Variations by race/ethnicity partly follow the pattern seen in women. African American and white men have almost the same age-adjusted incidence rates (1.3 vs. 1.0 per 100,000 men, respectively), but African American men under age 65 have a higher incidence than white men. Median age at diagnosis in California during the five years, 1992-1997, was 64 among African American men, compared to 70 among white men.<sup>13</sup> Routine screening is not recommended for men due to the rarity of the disease in this gender.

### Status of Cervical Cancer

#### Incidence and Mortality

The California Cancer Registry (CCR) estimates that in 2000 approximately 1,760 California women will be diagnosed with invasive cervical cancer, i.e. at a later stage when treatment is more complex, and 490 women will die from this disease.

FIGURE 3 - Cervical Cancer Age-Adjusted Female Mortality Rates per 100,000 Population by Year and Race/Ethnicity, California 1988-1997



Source: California Cancer Registry, June 2000.

## A SNAPSHOT

Since introduction of the Pap smear 50 years ago to detect pre-invasive lesions, the death rate for cervical cancer has declined 70%. Failure of early detection accounts for all cases of invasive cervical cancer. At one time, cervical cancer was one of the most common causes of cancer death for American women. Now, it is the ninth most deadly cancer.

As with breast cancer, cervical cancer incidence and death rates differ by race and ethnicity. See Figure 3. Overall, the incidence and mortality for invasive cancer of the cervix have declined steadily over the past three decades. Nonetheless, Hispanic, Asian-Pacific Islander, and African American women continue to experience invasive cervical cancer rates that are 50-120% higher than those of white women.

When cervical cancer is diagnosed and treated in its earliest, noninvasive stage, the in situ stage, the five-year survival rate approaches 100%. Early detection and timely treatment also improve the five-year survival rate for patients with invasive cervical cancer. Although statewide survival rates for invasive cervical cancer are not available, average survival rates for the Bay Area of California are shown in Table 2 below.

**Table 2**

*Five-Year Relative Cancer Survival Rate (%) for Invasive Cervical Cancer, Bay Area, California, 1987–1994*

Cancer Type	All Stages	Localized	Regional	Distant
Cervix	69	91	52	*

Source: American Cancer Society, California Division, and Public Health Institute, California Cancer Registry. California Cancer Facts and Figures 1999. Oakland, CA: American Cancer Society, California Division, September 1998. \*NA or <5 cases.

Racial differences are also evident in survival statistics; African Americans have a 59% five-year relative survival rate for invasive cancer compared with 72% for whites.<sup>14</sup>

*Since introduction of the Pap smear 50 years ago to detect pre-invasive lesions, the death rate for cervical cancer has declined 70 percent.*

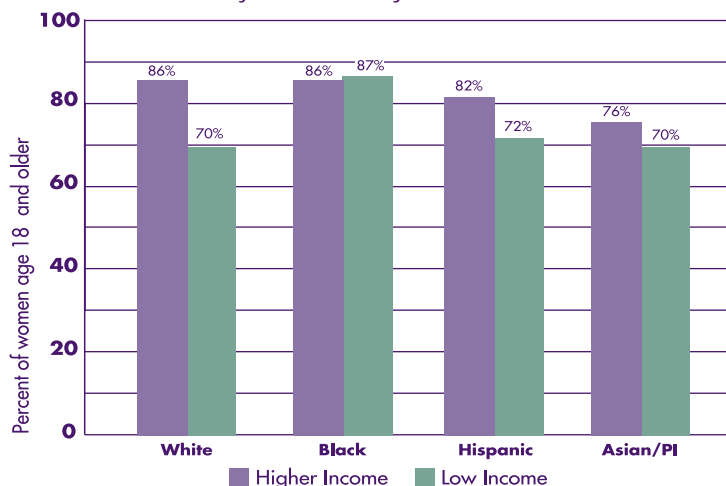
*50 years after the introduction of the Pap smear...12% of low income women had never had a Pap smear.*

### Screening

Almost all deaths from cervical cancer could be prevented by appropriate, regular, high quality screening with Pap smears and pelvic examinations. Yet 50 years after the introduction of the Pap smear, substantial percentages of California women report not having had Pap smears at expected intervals, and 12% of low income women had never had a Pap smear.

FIGURE 4 - Percent of women age 18 and older who had a Pap Test within the past two years, California 1997

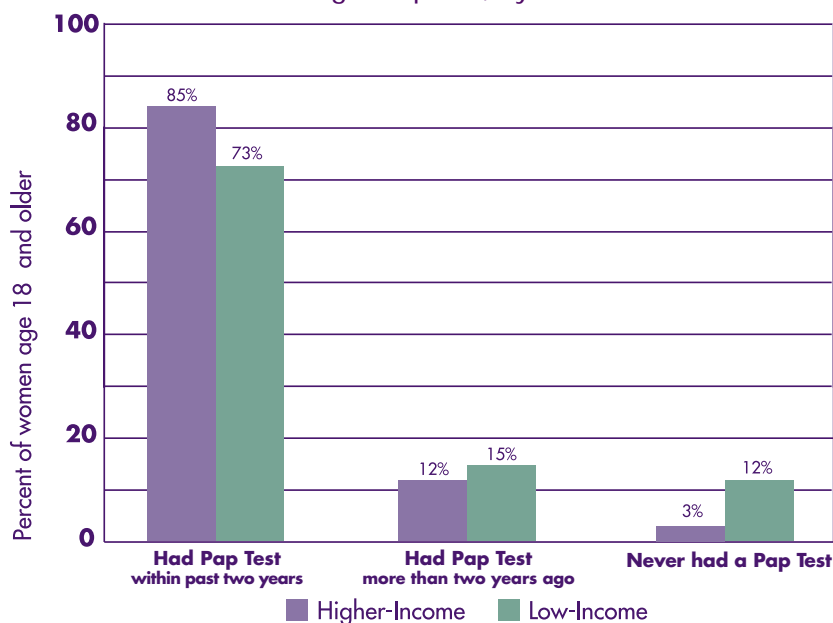
By Race, Ethnicity and Income Status



Source: 1997 California Women's Health Survey. Low income is defined here as household income at or below 200% of the federal poverty level.

The decline in cervical cancer death rates has been less substantial for populations where screening is less prevalent, such as African American women, elderly African American and white women, and middle-aged poor women.<sup>15,16</sup> It is also generally

FIGURE 5 - Percent of women age 18 and older who reported having and never having a Pap Test, by income status



Source: 1997 California Women's Health Survey. Low income is defined here as household income at or below 200% of the federal poverty level.

## A SNAPSHOT

agreed that Native Americans, Hispanic women, adolescents, women who live in rural areas, women who do not speak English, Asian/Pacific Islanders, and lesbians are underserved with respect to cervical cancer screening.

Case-control studies have found that the risk of developing invasive cervical cancer is 3-10 times greater in women who have not been screened. Also, the risk of developing invasive cervical cancer increases as the time since the last normal Pap smear increases or as frequency of screening decreases. While screening programs have improved screening rates, lack of appropriate follow-up, reduced screening frequency, or discontinuance of screening by providers is a problem, particularly for women of lower socioeconomic status. Women who are seen in outpatient clinics, emergency rooms, inpatient units, and urgent care facilities are often not screened for cervical cancer, despite the need and opportunity.

### Risk and Risk Factors for Female Breast Cancer

#### *Risk Status*

The risk of developing breast cancer and the risk of being diagnosed with breast cancer are used interchangeably in this Plan. Lifetime risk is the probability that a newborn female will be diagnosed with breast cancer sometime during her life. Interval risk is the probability that a woman who is cancer-free at a certain age will develop breast cancer within a specified number of years.<sup>17</sup>

#### *Lifetime Risk by Race/Ethnicity*

The estimated lifetime risk of developing invasive breast cancer for women in California is shown in Table 3 below. The estimated lifetime risk for white women in California is 1 in 7. In contrast, the lifetime risk for Asian/Other women is substantially lower, with an expected 1 in 13 developing breast cancer over a lifetime. Lifetime risk for African American and Hispanic women is 1 in 10 and 1 in 12, respectively.<sup>18</sup> These results are similar to lifetime risk estimates published by the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program.

**Table 3**

*Cumulative Risk from Birth of Being Diagnosed with Invasive Breast Cancer, for Women, by Age and Race/Ethnicity, California, 1988–1992*

Birth to Age	All Races one in:	Asian/Other one in:	African American one in:	Hispanic one in:	White one in:
30	2,451	4,445	1,443	2,890	2,558
35	623	709	443	721	614
40	227	259	176	272	218
45	101	121	85	134	94
50	53	65	49	74	48
55	34	44	33	49	31
60	24	34	24	34	22
65	18	27	19	27	16
70	14	22	16	21	12
75	11	19	14	17	10
80	10	16	12	15	9
85	9	15	11	13	8
Lifetime	8	13	10	12	7

Source: California Cancer Registry. November 1994.

***The most important risk factors for breast cancer are being female, increasing age, and family history of breast cancer.<sup>21</sup>***

Based on these estimates, one in eight California women can be expected to develop invasive breast cancer in her lifetime, an estimate very similar to that based on national data. However, the risk accumulates over a woman's entire life, and is not experienced each year. For example, the risk of developing invasive breast cancer for the first time in the next 10 years is 1 in 53 for a 50 year-old woman, and 1 in 24 for a 60 year-old woman.<sup>19</sup> It has been shown that many women overestimate their short-term risks<sup>20</sup>, which may lead to unjustified fear and anxiety. Consequently, it is important that women of different age and race/ethnic groups be accurately informed about their projected risks of developing breast cancer.

### ***Risk Factors***

#### *Gender, Age and Family History*

The most important risk factors for breast cancer are being female, increasing age, and family history of breast cancer.<sup>21</sup> The older a woman is, the greater her chance of getting the disease. Women aged 65 years and older are the most likely to develop and die from breast cancer. Nearly half of all breast cancer patients and over half of the deaths from breast cancer are in senior women.<sup>22</sup> If either a woman's mother or sister has breast cancer, the woman's risk increases about two to three times and may be higher depending on the age at which that the relative was diagnosed. Having both a mother and a sister with breast cancer increases a woman's risk up to six-fold.<sup>23</sup>

#### *Reproductive Factors*

It is well recognized that certain reproductive events, and the age at which they occur, are predictors of subsequent breast cancer risk. The most consistent predictor of risk in various populations is the woman's age at first full-term pregnancy. Women with a full-term pregnancy after age 30, and women who have never borne a child have about a two- to three-fold increased risk of breast cancer compared to women having a full-term pregnancy before age 20. The greater number of women who are delaying childbirth or remaining childless may explain some of the recent increased incidence of breast cancer.<sup>24</sup> Groups with greater nulliparity, such as lesbians, may be at higher risk of breast cancer. The effect of lactation is becoming clearer and suggests there is a reduction in risk directly associated with lifetime months of breastfeeding.<sup>26</sup> These reproductive factors are thought to affect the risk of breast cancer by their effects on a woman's hormonal status.

#### *Genetic Factors*

Genetic factors are known to play a role in some women's risk of developing breast cancer. However, only between 5%-10% of all breast cancers seem to be attributable to an inherited genetic mutation.<sup>27</sup> Mutations in at least five genes can predispose women to breast cancer.<sup>28</sup> Two breast cancer genes, BRCA1 and BRCA2 are the most widely recognized. Current estimates of the risk of breast cancer in a woman who carries a BRCA1 or BRCA2 mutation and is from a kindred with multiple cases of breast or ovarian cancer, or both, range from 76% to 87%.<sup>29</sup>

## A SNAPSHOT

However, a study of one high-risk group of women estimated the risk of breast cancer among carriers of one of three BRCA1 and BRCA2 mutations as 33% by age 50 and 56% by age 70, below prior estimates of the risk of cancer among carriers of BRCA1 and BRCA2 mutations from families with breast cancer.<sup>29</sup>

### *Other Factors*

A woman's risk for developing breast cancer may also be increased by a history of biopsy-confirmed benign breast disease, obesity after menopause<sup>31</sup> and/or physical inactivity, and drinking moderate to high amounts of alcohol daily.<sup>32</sup>

Men share some of the same risk factors as women, particularly family history, some of which are associated with recently identified breast cancer susceptibility genes, particularly BRCA2. Ionizing radiation and a history of benign breast disease such as atypical hyperplasia also have been shown to increase risk in men as well as in women.<sup>33</sup>

While many factors have been associated with the risk of breast cancer, most increase risk only moderately, suggesting that multiple factors may exist. About 40%-60% of the risk of breast cancer can be explained by current knowledge, indicating the need for further research.<sup>34</sup>

## Risk and Risk Factors for Cancer of the Cervix

Unless a woman has had surgical removal of the cervix (e.g., hysterectomy) she is at risk for developing cancer of the cervix. However, older women—because they are beyond childbearing age are less likely to have pre-cancerous lesions detected through regular checkups—and sexually active adolescents—because they frequently engage in unprotected intercourse—are at higher risk.

### *Sexual Behavior and Sexually Transmitted Disease*

Sexual behavior has been identified as the major risk factor for both carcinoma in situ and invasive cervical cancer. Risk of both conditions is increased in women reporting either early age at first intercourse or numerous lifetime sexual partners. Early onset of sexual activity is thought to be associated with high risk because pubescent cervical tissue is more vulnerable to infection by sexually transmitted agents. Early intercourse is usually associated with the eventual number of sexual partners; the greater the number of sexual partners, the greater the risk of sexually transmitted agents. Despite early speculation regarding potential effects of a "male factor" in this disease, recent studies do not confirm a role for circumcision status of the male partner.<sup>35</sup>

Recently, intense interest has focused on the role of the human papillomaviruses (HPV), which cause genital warts in both men and women. Although the natural

***About 40%-60% of the risk of breast cancer can be explained by current knowledge, indicating the need for further research.<sup>34</sup>***

history of HPV is unknown, a strong relationship between certain types of HPV and cervical cancer and its precursors has been established.<sup>36</sup> In a number of studies, cigarette smoking has been found to increase the risk of cervical cancer, especially among long-term or high-intensity smokers.<sup>37</sup> Choice of contraceptive method also appears to affect the risk of cervical cancer. Barrier contraceptives/methods lower the risks, probably by decreasing exposure to infectious agents. There is increasing evidence that nutritional factors may play a role in cervical disease. Several studies suggest that low intake of either vitamin C or beta carotene may be associated with elevations in risk.<sup>38</sup>

### Barriers To Early Detection And Treatment

Despite the proven effectiveness and widespread promotion of screening mammography and Pap smear screening, many women at risk are not being screened for breast and cervical cancer on a regular basis. Those least likely to be screened are low-income women, less educated women, women who are less acculturated, and women aged 65 and older. A number of patient-related, provider-related, and health care system-related barriers, all of which can be correlated with health outcomes, prevent utilization of screening and treatment services.

An extensive review of the literature examined barriers to care in the entire continuum of breast cancer care – screening, follow-up of abnormal results, diagnosis, treatment, and survivorship – that also apply as barriers affecting cervical cancer care. The research demonstrated that barriers experienced at any point along this continuum can have an impact on breast and cervical cancer outcomes—objective outcomes, such as mortality, and subjective outcomes such as quality of life. There is naturally some overlap, as barriers affecting one segment of the continuum may also affect others. The scientific literature in the last decade also reveals a number of obstacles to breast screening services for women as well as for providers, which can be reduced through improved patient-provider communication approaches.<sup>40</sup>

#### Provider-Related Barriers

Lack of provider recommendation is the provider-related barrier most often cited by women, particularly older women and women of color, for not seeking screening services. Although primary care physicians are generally knowledgeable about breast cancer screening guidelines, they often do not recommend screening to their patients. In addition, the physician's or nurse practitioner's style of communication and enthusiasm in recommending mammograms influences a woman's screening behavior significantly. Inadequate training, lack of skills to perform screening procedures, and lack of knowledge on how to counsel patients are provider-related barriers to screening; provider delays in diagnosis or treatment occurring while symptomatic women are within the provider's care are also provider-related barriers to treatment services. The lack of availability of female and bicultural providers has been noted to be a significant barrier for some older, non-acculturated Hispanic and Southeast Asian women for reasons like the value they place on modesty and privacy.

*The research demonstrated that barriers to early detection and treatment experienced at any point along this continuum can have an impact on breast and cervical cancer outcomes—objective outcomes, such as mortality, and subjective outcomes such as quality of life.*



## A SNAPSHOT

### *Patient-Related Barriers*

Patient-related barriers include the fears, anxiety, embarrassment, and other emotional responses of a woman considering or undergoing screening or treatment. Embarrassment associated with clinical breast exam and mammography, for example, has been noted as a barrier among older women of all cultures. Inaccurate risk perceptions and elevated levels of psychological distress among relatives of breast cancer patients may serve as barriers to mammography use in this population, who have surprisingly low rates of mammography, despite their increased risk.<sup>42</sup>

### *Sociocultural Barriers*

Sociocultural barriers include the woman's knowledge and beliefs about breast and cervical cancer, the role of the family, and cultural perspectives that help or hinder screening and treatment behavior. The literature published on American Indian women and cancer emphasizes that traditional American Indian perspectives of disease and health differ greatly from the Western medical model, for instance. Demographic variables, such as the level of education, socioeconomic status and location of residence, can also be barriers to a woman's ability to access services. Breast and cervical screening rates have also been shown to be low among women who are monolingual and do not speak English.<sup>43,44,45,46,47</sup>

### *Financial Barriers*

Among the most frequently cited barriers that hinder women with breast changes from seeking care are financial difficulties. When patients attempt to follow screening and treatment guidelines, payment barriers can deter them from obtaining appropriate screening, diagnosis, and treatment. These barriers include:

- Lack of money for out-of-pocket health care expenses, especially prevention or screening;
- Lack of health insurance;
- Insurance does not cover prevention education or screening;
- Insurance covers all or part of the cost of the screening only if the woman has met the deductible amount;
- The patient's insurance does not cover, or charges a higher premium, for pre-existing health conditions, such as cancer.

With full insurance coverage for medical care, a patient is much more likely to seek care for breast cancer symptoms. System delay—the interval between initial medical consultation and diagnosis and treatment—based on patients' ability to pay may account for some survival differences between different races or ethnic groups.

### *Structural and Functional Barriers in The Health Delivery System*

Some degree of low participation in screening can be attributed to structural and functional barriers in the delivery system. Long waits for an appointment or during a visit and limited availability of physicians, clinics, and hospitals significantly lower screening rates. Not knowing where to go for care, inability to take time off from work to visit the provider, the need for child care, and transportation are other important practical barriers to breast and cervical cancer screening and treatment services.

*Some degree of low participation in screening can be attributed to structural and functional barriers in the delivery system. Long waits for an appointment or during a visit and limited availability of physicians, clinics, and hospitals significantly lower screening rates.*

## Treatment and Quality of Life

Breast cancer treatment depends on the type of breast cancer, how far it has spread, the woman's age, menopausal status and general health. Breast cancer is treated with one or more of the following modalities: surgery (a lumpectomy, local removal of the tumor, or mastectomy, removal of the breast); radiation therapy (high energy x-rays to damage or stop the growth of cancer cells); chemotherapy (a systemic treatment that uses one or a combination of drugs to kill cancer cells); and hormone therapy (drugs that keep the tumor from getting hormones that promote cancer cell growth).

The type of treatment for cervical cancer depends on several factors, including stage of the disease, age, and the general health of the woman. Like treatment for breast cancer, cervical cancer treatment may involve surgery, radiation therapy, and/or chemotherapy. Treating premalignant conditions of the cervix may include cryosurgery (freezes and destroys abnormal tissues), cauterization (uses heat to destroy abnormal tissues), laser treatment, hysterectomy, or loop electrical surgical excision procedure (LEEP), a procedure in which electrical wire loops the lesion and the tissue is available for microscopic analysis.<sup>48</sup>

### *Clinical Trials*

Many advocates believe that there is a need for greater willingness among health care providers and the public to support clinical trials of cancer therapies. Enrollment in a clinical trial or National Cancer Institute (NCI)-approved protocol often affords the cancer patient the very best therapy available. Yet, some eligible patients are unwilling to participate in clinical trials, and physicians may neglect to refer them to appropriate and available protocols. It has been estimated that less than 3% of cancer patients under treatment in the U.S. are enrolled in clinical trials. In one NCI-sponsored study of clinical trial participation, about half of the patients were not enrolled because of physician non-compliance, and one-third refused to participate because of concerns about experimentation, toxicity and cost. Physician refusals tended to reflect a preference for a specific alternate therapy. In general, cancer patients who participate in clinical trials tend to be white, young and to have advanced disease.<sup>51</sup>

### *Quality Of Life*

As cancer treatments become more successful in extending life, the demand for the quality of this extended survival has increased. There is growing consensus within the health care community that quality of life (QOL) involves individuals' subjective experiences and is multidimensional in nature. Although no one global definition can capture the true status of quality of life, there is conceptual agreement that it at least includes dimensions of physical, mental, social, economic, psychological and spiritual well being.<sup>52</sup> Counseling, support groups, access to rehabilitative services, techniques for symptom management, and long-term follow-up all may influence the quality of life of the cancer survivor.<sup>53</sup>

*There is growing consensus within the health care community that quality of life (QOL) involves individuals' subjective experiences and is multidimensional in nature.*

## GOALS, OBJECTIVES & STRATEGIES



## Criteria for Strategy Development

The first responsibility of the Task Force was to establish criteria for determining Plan priorities. Given the magnitude of the burden of breast and cervical cancer in California, and the size and diversity of the target population, it was clear that criteria for strategy development would be necessary, particularly when considering future development and allocation of needed resources to carry out this Plan. The following criteria were established:

- Implementation of the strategy can occur within the next five years, but should not be limited to addressing only those issues that can be resolved within this timeframe. The strategy should be a visionary statement that lends itself to an action Plan with concrete steps.
- The strategy lends itself to evaluation and outcome measures that may be qualitative or quantitative, and is open to different methodologies for tracking and monitoring beyond self-reporting.
- The strategy addresses significant gaps and disparities and reduces disease burden.
- The impact of the strategy is statewide, not just local or regional.
- The strategy promotes broad-based collaborative efforts and identifies the resources to make it successful.
- The strategy draws from and builds on evidence where such evidence exists of a relationship to the reduction of breast and cervical cancer morbidity and mortality. Where important evidence is missing, build a strategy to research and develop evidence.
- The likelihood of replication of the strategy is high.

Applying these criteria, the Plan Task Force identified the following goals, objectives, and strategies for the five-year implementation period January 2000-December 2004. The Plan is flexible and anticipates that additional strategies will emerge as the needs of communities become better understood, as policy changes occur, and the results of studies become known. The proposed strategies presume that existing efforts will be identified and built upon.

To better understand the strategic options, the reader should be aware of the thinking and rationale of the Task Force on several issues.

- The order in this section of the Plan follows the continuum of cancer control Risk Reduction/Prevention, Detection, and Treatment. In public health thinking, risk reduction/prevention is the initial goal.

## GOALS, OBJECTIVES & STRATEGIES

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- The strategies and objectives for each goal are not listed by any particular priority, but are deliberately unranked for several reasons: the majority of the Task Force members were resistant to trying to prioritize the strategic direction; the criteria for making priority determinations were viewed as difficult to identify and agree on; the Task Force may be viewed by the field as proportionately unrepresentative, although the goal was to convene a representative group; what might be viewed as a high priority by one group may not be viewed as highly by another; and organizations would ultimately decide which work to undertake based on their own mission and business objectives.
- While the Task Force acknowledged that breast cancer affects both men and women (about one percent of men's cancer is cancer of the breast), they believed the overwhelming magnitude of the disease in women justified the development of strategies that are predominantly directed toward women. Some of the recommended strategies are intended to be gender neutral, however, and these are implied through the use of words such as "patient," "client," or "the general public."
- Generally, the Plan addresses all those affected by breast and cervical cancer. However, because some women are at higher risk for these two cancers, many of the strategies are by necessity directed to them. The affected groups are those who because of various personal or systems barriers, including attitudes, are less likely to be reached with timely health messages and services, less able to pay for recommended services, and under-represented in research projects. Some characteristics associated with these underserved populations may include: low income, inability to speak or understand English, low literacy, age past child bearing, lesbian or bisexual, disability, newly arrived immigration status, inadequate or no health insurance, and homelessness.
- The Task Force recognized that while some of the objectives have common themes and cut across all of the Committees' interests—such as, participation in clinical trials, scientific communication, and education for women—the action steps necessary to implement the strategies are mostly unique for each area.
- Finally, in considering the development of the strategies, each of the Task Force Committees encountered challenges unique to their section of the Plan that in some cases required lengthy discussion and debate before majority agreement was reached. These areas of controversy are acknowledged at the beginning of each of the three sections.

## RISK REDUCTION AND PREVENTION



## RISK REDUCTION AND PREVENTION

While the link between smoking and lung cancer is clear, altering diets and promoting exercise to reduce the risk of breast cancer continues to be debated in the scientific community. Less widely known, but clearly linked, are two risks for cervical cancer: smoking and infection by the human papillomavirus (HPV). Detection and treatment for both breast and cervical cancer are more widely understood, and most people are familiar with these areas.

However, prevention is believed to hold the most promise, even though it has a lesser body of definitive evidence supporting its effectiveness. One difficulty is that when cancer risks are reduced through preventive strategies, such as lifestyle or behavior change, it may take many years to observe the impact on cancer rates. This delay is also a barrier to assessing prevention efforts directed at the cancers known or suspected to be attributable to environmental factors.

The influence of environmental (non-workplace and workplace) exposure to human carcinogens on the incidence of breast and cervical cancer was discussed at length by the Risk Reduction/Prevention Committee. It can take as long as 20 to 30 years for the health effects of exposures to environmental carcinogens—including air, water, and soil contaminants—to become clinically apparent, and this long latency period makes it difficult to identify direct causal factors. Because the risks of many of these influences are inconclusive at this time, but may be significant, the Committee believed further study was warranted, and supported additional research for several of the prevention objectives in this section.

The Committee also spent many hours discussing the current understanding about the genetic contribution to cancer susceptibility and the limitations to what genetic testing is likely to achieve. Clinical genetics has recently been one of the most rapidly developing fields in health care. Current trends in molecular biology research and development, the commercial interests of science, and the progress of the Human Genome Project are stimulating novel research protocols, screening, diagnostic technologies, and therapeutic agents. Greater understanding of the genetic and environmental influences on health and disease may make it possible in the near future to know the conditions to which individuals and family members are predisposed. At the same time, the availability of new genetic screening technologies may also lead to unnecessary interventions or denial of health insurance.

Women are requesting more information about genetic technologies—what they can and cannot reveal, their accuracy, and potential benefits and risks—as well as the personal and social implications, in order to make informed decisions about cancer gene testing. Primary care providers are expected to interpret medical developments, identify and counsel patients and offer referrals for specialized care. Consequently, the Committee framed a number of strategies to address professionals' needs for information about current and future strategies to minimize risk, and women's needs for knowledge and access to appropriate services in the area of genetics and cancer.

Some studies are presently evaluating vaccines that would prevent or cure the pre-cancerous lesions induced by genital oncogenic human papillomaviruses (HPVs). Although the majority of Committee members believed it would be premature to frame strategies now for their use, they agreed that the flexibility of the Plan allowed for future consideration of any vaccines that may be approved within the next five years.



**To prevent or delay development of breast and cervical cancer in California.**

## GOAL

To prevent or delay development of breast and cervical cancer in California.

## OBJECTIVES

### *Objective 1. Behavioral Risk Reduction*

To promote behaviors associated with reduced risk of breast and cervical cancer through education and policies.

#### *Strategies:*

1. Support research that explores and identifies relationships between public policy and risk reduction, such as funding of school sports programs for girls and its impact on lifetime exercise patterns.
2. Inform policymakers about the impact of public policy on risk reduction, such as workplace practices that discourage breastfeeding or on-site child care that might delay childbearing, possibly increasing the risk of breast cancer, and advocate for appropriate policy changes.
3. Increase the inclusion of accurate information about the relationship of smoking and cervical cancer in tobacco cessation program efforts.
4. Promote policies in communities, schools and the workplace and provide the means that encourage increased exercise and maintenance of target body weight, such as safe places to exercise.
5. Educate women and girls about their bodies, and the association of exercise, maintenance of target body weight, and alcohol use with the risk of breast cancer.
6. Inform providers about their unique opportunity to influence women's behavior, and encourage them to use the provider/patient relationship to facilitate risk-reducing behaviors.
7. Support educational activities for young men and women about cervical cancer risk reduction behaviors, such as avoiding or stopping smoking, delaying intercourse until later age, limiting the number of sexual partners, and using condoms to reduce transmission of human papillomaviruses (HPVs).

### *Objective 2. Environment*

To increase knowledge about environmental influences that may contribute to breast and cervical cancer.

#### *Strategies:*

1. Fund and support increased research into the roles of endogenous and environmental (synthetic and naturally occurring) estrogens and their interactions in relation to breast cancer risk.
2. Create or support an ongoing environmental health task force whose purpose would be to review available literature, recommend state policy based on precautionary principles\* about use of synthetic compounds and classes of compounds in the environment, and identify future research needs.

\* The "precautionary principle" or "precautionary approach" is the concept of taking anticipatory action, or precautionary measures, when an activity raises threats of harm to human health or the environment even if some cause and effect relationships are not fully established scientifically.

## RISK REDUCTION AND PREVENTION

### ***Objective 3. Medical Risk Reduction***

To ensure the appropriate use and accessibility of risk reduction medications (e.g., chemo-preventive agents) and prophylactic mastectomy, and to prevent inappropriate use of these breast cancer prevention modalities.

#### *Strategies:*

1. Support and promote risk assessment research that improves the ability to identify and advise women at high risk for breast cancer.
2. Support educational activities to improve health providers' capability to conduct risk assessment and to counsel women about the benefits, drawbacks, and medical appropriateness of specific preventive and risk reduction measures.
3. Support culturally sensitive educational activities for women that promote accurate information about their personal risk status and the risks and benefits of specific risk reduction measures.
4. Provide adequate reimbursement by all payors to cover the cost of specific preventive and risk reduction measures.
5. Review and, if appropriate, disseminate once they are available to the health care community and general public the U.S. Preventive Health Services Task Force guidelines on chemopreventive agents.

### ***Objective 4. Scientific Communication***

To promote innovative research through increased exchange of scientific ideas and information among the various research disciplines, such as occupational and environmental health and breast and cervical cancer researchers, and consumer advocates.

#### *Strategies:*

1. Host a biennial statewide symposium on cutting edge breast and cervical cancer prevention research, and disseminate findings through fact sheets, position papers and the Internet.
2. Increase research funds for multidisciplinary, innovative, collaborative and translational research.

### ***Objective 5. Genetic Testing***

To ensure appropriate use and access to genetic testing for breast cancer, and to prevent inappropriate use of these tests for breast cancer.

#### *Strategies:*

1. Support education programs for primary care providers about new developments in cancer genetic screening, diagnosis and treatment, in addition to the associated ethical, legal and social issues.

2. Promote educational programs for primary care and other providers that enhance genetic counseling skills, including information on how to take a comprehensive family/genetic/environmental health history to assess cancer risks and to make appropriate referrals.
3. Conduct a special education campaign using print and electronic media to increase women's awareness of the possible benefits and limitations of predictive genetic testing.
4. Improve access to genetic information and counseling for all women so that they can make informed choices about genetic testing.
5. Assess specific challenges and develop specific actions to protect women from disclosure of genetic information that could lead to discrimination against them and their families.

### ***Objective 6. Clinical Trials***

To increase the number and diversity of women who participate in clinical prevention trials.

#### *Strategies:*

1. Increase the number of advocacy representatives in the design of clinical trials.
2. Provide appropriate reimbursement in funded research to cover the cost to the woman of participating in a trial, such as transportation, childcare, translation services, time lost from work, and other barriers that preclude participation.
3. Institute reforms in the insurance industry to assure non-discrimination toward women who participate in clinical trials.
4. Institute and support a statewide database of available clinical trials related to breast and cervical cancer prevention.
5. Educate providers about the availability of and findings from clinical prevention trials, and encourage them to refer women to participate.
6. Educate women about the availability of clinical prevention trials, including information about the risks and benefits of participating, and tailor these activities to under-represented populations.
7. Ensure reimbursement in funded research to cover the providers' costs of participating and referring women, such as data management and staffing and other overhead costs that act as barriers.

### ***Objective 7. Basic and Epidemiological Research***

To promote and support more basic and epidemiological research into the cause and prevention of breast and cervical cancer.

#### *Strategies:*

1. Identify the co-factors associated with human papillomavirus (HPV) that allow the development of cervical dysplasia and cancer.

## DETECTION

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The earlier breast and cervical cancers are detected, the greater the chance for survival. Since early diagnosis and treatment are associated with decreased breast cancer mortality, it is important to minimize the times from detection to diagnosis to treatment.<sup>54</sup> The American Cancer Society and other experts agree that mammography and clinical breast exam (CBE), when properly and regularly done, are the most effective screening tools to prevent breast cancer deaths. In spite of the value of these detection methods in reducing morbidity and mortality, there is still a need for better methods to detect breast cancer early.

While breast self-exam (BSE) is currently taught in the community as part of the triad of BSE, clinical breast exam (CBE), and mammogram, the Detection Committee did not specifically recommend BSE in any detection strategies. The Committee recognized the historical and personal value and other benefits of this procedure by women who have discovered their own cancers, but elected after lengthy discussion to not address BSE as a strategy in this Plan because scientific evidence shows no clear relationship of regular BSE in reducing breast cancer mortality,<sup>55,56,58</sup> although it has been shown in one study of African American women to be the most important predictor of having a mammogram.<sup>58</sup> The Committee affirmed that the monthly practice of BSE can make women more aware of their breasts, and may help them overcome some of the barriers to seeking breast cancer screening services.

While the Pap smear provides an important opportunity today to prevent or delay progression of cervical disease, adjunct tests to the Pap smear (e.g., technologies for computer-assisted Pap smear screening) are emerging that may be efficacious and cost-effective. To allow for the possibility of population-based screening by such technologies within the next five years, the Detection Committee elected to use the generic term, "cervical cancer screening," in place of "Pap smear" for the cervical screening strategies in this section of the Plan.

Because of the enormous diversity among populations in California, a key component to many of the strategies in this section is developing customized programs and approaches for specific groups, such as women who have not had a mammogram in the past two years or women who have never had cervical cancer screening services. To reach these populations, more tailored patient-level, systems-level, and community-level strategies have been recommended in this section of the Plan.

## DETECTION

### GOAL

To promote, increase, and optimize the availability and appropriate utilization of high-quality breast and cervical cancer screening and follow-up services.

### OBJECTIVES

#### *Objective 1. Knowledge and Behavior*

To increase knowledge and skills, and to change attitudes and behaviors, that promote breast and cervical cancer screening, particularly for women who underutilize these services.

#### *Strategies:*

1. Design, implement and evaluate a comprehensive, coordinated statewide breast and cervical cancer outreach initiative, especially focusing on women who are less acculturated and non English-speaking, and assist communities to develop their own localized campaigns that incorporate media and use best practices from successful local campaigns.
2. Develop, implement and evaluate a standardized breast and cervical cancer health education curriculum based on evidence of effectiveness, with modules tailored to the characteristics of specific affected subpopulations.
3. Develop and support programs that deliver a standardized breast and cervical health education curriculum to underserved populations who do not use or have access to traditional methods of health outreach.
4. Identify gaps in educational and promotional materials, and develop, or adapt from existing materials as appropriate, print and electronic educational materials needed to reach affected subpopulations.
5. Create and maintain a clearinghouse for culturally-appropriate state-of-the-art breast and cervical cancer educational and promotional materials, and ensure that the process builds on existing efforts for evaluating new materials and takes culture, literacy and linguistics into account
6. Provide technical assistance and training to community organizations and health care providers who serve women about how to use specially tailored educational materials.
7. Support and evaluate innovative approaches that address gaps in effective outreach and educational strategies, and disseminate findings of promising results, including data on cost-effectiveness.
8. Identify and support the expansion of effective community-based programs that change attitudes and build skills, such as church-based projects, the "Promotores" and "Tell-a-Friend" programs, and peer counseling.
9. Expand educational programs for women to include information about new breast and cervical cancer screening and diagnostic technologies that are effective.
10. Design, implement and evaluate community and provider-based mammography screening programs to inform health care providers and older women about the new enhanced Medicare mammography benefit, and educate providers about the unique needs of older women.
11. Promote coordination of outreach efforts by different organizations to ensure consistent messages, based on proven effectiveness, and maximize outreach impact on intended audiences.

**To promote, increase, and optimize the availability and appropriate utilization of high-quality breast and cervical cancer screening and follow-up services.**

***Objective 2. Personal and Systems Barriers***

To decrease patient, provider and system-related barriers to breast and cervical cancer screening.

***Strategies:***

1. Establish an ongoing funding base to enable 100% of women with little or no health care coverage to receive no-cost breast and cervical cancer screening services and offer incentives (financial and other) for providers to serve these women.
2. Review and implement changes in programs that serve low-income populations, such as the Breast Cancer Early Detection Program (BCEDP)/ Breast and Cervical Cancer Control Program (BCCCP), to streamline the administrative procedures that act as disincentives to providers from offering or recommending cancer screening services.
3. Develop a simplified eligibility process that facilitates access for low-income women to publicly-funded screening services.
4. Support educational programs for providers and other health care personnel that emphasize provider/patient communication, sensitivity, respect, and up-to date information about breast and cervical health care.
5. Support programs that reduce infrastructure and personal barriers, such as transportation, geographic distance, language, cost and childcare.
6. Support training programs that increase the sensitivity of mammography technologist staff to address women's discomfort during screening.
7. Disseminate information to women about available mammography and cervical cancer screening benefits and how to access them, especially those services covered by Medicare and Medi-Cal.
8. Support innovative community-based "patient navigation" programs that facilitate access to screening services for all women.

***Objective 3. Screening at Appropriate Intervals***

To ensure that all women receive breast and cervical cancer screening at appropriate intervals, and understand the benefits and limitations of these services.

***Strategies:***

1. Promote the use of effective and innovative reminder and tracking systems by providers to inform women of their need for follow-up and re-screening services.
2. Disseminate guidelines to women about recommended breast and cervical cancer screening intervals to increase their ability to make informed decisions about their care in consultation with their primary care provider.
3. Educate women about personal risk factors in order to discuss appropriate intervals for breast and cervical cancer screening with their providers.
4. Promote public reporting of screening rates and other quality indicators via HEDIS or similar publicly-reported data sets.

***Objective 4. First Cervical Screening***

To ensure that women who have never had cervical cancer screening services receive their first test as appropriate.



## DETECTION

### *Strategies:*

1. Collect, analyze and disseminate data about knowledge, attitudes, practices and barriers on subgroups of women who would be unlikely to have ever received a cervical cancer screening test, such as newly-arrived immigrants and lesbians.
2. Support tailored outreach efforts to underserved women with culturally appropriate educational messages and approaches that link them with available screening services.
3. Develop and disseminate educational materials and media messages tailored for underserved groups of women.
4. Promote cervical cancer screening and follow-up programs based in hospital emergency rooms.

### ***Objective 5. Follow-Up***

To ensure that all women who have an abnormal breast or cervical cancer screening finding obtain appropriate follow-up diagnostic and treatment services in a timely manner, with special attention to women at risk of being lost to follow-up.

### *Strategies:*

1. Disseminate, promote more broadly, and update as necessary the State Cancer Detection Section's *Breast Diagnostic Algorithms for Primary Care Clinicians* for breast cancer diagnosis.
2. Support and expand the availability of efforts like peer advocacy and case management that identify women with abnormal findings and link them with timely and appropriate diagnostic and support services.
3. Secure financial resources sufficient to ensure access for all women with abnormal findings to complete the full range of diagnostic services recommended.
4. Revise the existing Department of Health Services' (DHS) comprehensive booklet, *A Woman's Guide to Breast Cancer Diagnosis and Treatment*, to increase the number of languages, and improve the readability level and cultural sensitivity to help women better understand their diagnosis and treatment options, and ensure the booklet is disseminated according to law.
5. Promote use of accurate, reliable, and timely tracking systems that document whether women have been informed of results, and that ensure appropriate follow-up services are delivered in an effective and timely manner.
6. Promote public reporting of follow-up rates by health plans, health systems and payors.

### ***Objective 6. Provider Recommendation for Screening***

To increase the percentage of health care providers who consistently recommend and motivate women to obtain appropriate breast and cervical cancer screening and re-screening services.

### *Strategies:*

1. Incorporate into basic and continuing medical education state-of-the-art information about breast and cervical cancer and providers' unique opportunity to influence women's health care behavior.

2. Support programs, materials, and systems for health care providers to educate them about the importance of their role, and how to most effectively use that role, in influencing women's health care behaviors.
3. Implement programs in non-primary care facilities where low-income women access care, such as emergency rooms, to encourage providers to identify women due for breast and cervical cancer screening, and provide or make referrals for these services.
4. Establish or expand referral networks for low/no cost screening services, and support mechanisms that help providers to make these referrals.

### ***Objective 7. Diversity of Needs***

To ensure that high quality breast and cervical cancer screening, information, education, and services are provided in a manner that is responsive to the diverse needs of the population of California.

#### *Strategies:*

1. Develop, provide and evaluate training programs for clinicians, health educators, administrators and support staff to promote culturally and linguistically competent care.
2. Conduct cultural and linguistic needs assessments, such as client satisfaction surveys and focus groups, to evaluate the degree to which women are receiving appropriate services specific to their needs, unbiased by age, culture or insurance status.
3. Modify existing or develop culturally and linguistically appropriate BCEDP/BCCCP consumer materials that are responsive to the diversity of California's population.
4. Create, maintain and disseminate to the medical and health care community and other caregivers a resource directory that provides information about breast and cervical cancer-related support services that are available in the community.

### ***Objective 8. Clinical Breast Exams***

To increase the knowledge and skills of health care providers on effective methods for conducting clinical breast exams.

#### *Strategies:*

1. Expand the dissemination of the Cancer Detection Section's continuing education module for primary care clinicians, "Clinical Breast Examination: Proficiency and Risk Management."
2. Incorporate comprehensive clinical breast exam technique and appropriate methods of follow-up of abnormal findings into basic and continuing clinical education instruction.

### ***Objective 9. Mammography Competence***

To increase the knowledge and skills of health care personnel in the performance and interpretation of mammograms.

## DETECTION

### *Strategies:*

1. Enforce the federal Mammography Quality Standards Act in any facility performing mammograms, including monitoring facilities for false negative and false positive rates.
2. Provide continuing education in collaboration with professional associations and educational institutions to increase the technical skills of mammography practitioners to perform and interpret mammograms.

### **Objective 10. Cervical Screening Competence and Capacity**

To increase the knowledge, skills, and availability of well-trained health care personnel to collect, store, transport, and read cervical cancer screening samples.

### *Strategies:*

1. Update and promote the State Cancer Detection Section's Cervical Diagnostic Algorithms for Primary Care Clinicians for cervical cancer screening and diagnosis based on the current state of knowledge.
2. Disseminate guidelines and training materials, such as videos, to medical students and clinical providers on proper cervical sampling, storage and transport technique.
3. Inform providers about new cervical screening technologies (e.g., liquid-based Paps, use of automated image analysis) and encourage their use as appropriate.
4. Support efforts to expand the number of cytotechnologists trained in California each year to increase laboratories' capacity to provide accurate and timely cervical cancer screening services.

### **Objective 11. Data**

To improve the systematic and comprehensive collection, analysis, and reporting of data that facilitates identification, targeting, and evaluation of breast and cervical cancer screening, interventions and quality of care.

### *Strategies:*

1. Promote the use of electronic medical records with special attention to protection of client confidentiality.
2. Promote a uniform billing system, particularly for State programs such as BCEDP/BCCCP.
3. Promote collection of standardized race/ethnicity data by Medi-Cal and Medicare.
4. Promote collaboration between government and private payors in the exchange of demographic and clinical data for analyses of such factors as quality, cost and utilization, with an emphasis on maintenance of patient confidentiality.
5. Promote public reporting of aggregate screening tests and other related quality of care measures, such as those found in HEDIS, to inform consumers, motivate providers, and foster accountability.
6. Enhance the resources of the California Cancer Registry to a comparable level of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) cancer database so that California can more effectively evaluate the cancer trends, incidence, mortality, treatment, patterns of care, and survival of all women with cancer.

**Objective 12. Reminder Systems**

To promote the use of patient and provider reminder systems for follow-up and re screening.

*Strategies:*

1. Support the development and use of computerized reminder and tracking systems as cues to providers to refer clients for screening and assist providers to comply with state and federal quality standards for rescreening and tracking and follow-up.
2. Support the implementation of manual reminder and tracking systems for providers who have limited electronic capacity, such as making available preprinted client reminder cards.
3. Provide start-up funds to safety net providers through loans or grants for the development and maintenance of tracking systems.
4. Support the development of a system-generated mailer, similar to dental practice guidelines, for reminders or recalls.

**Objective 13. Research and Public Policy**

To promote research into new breast and cervical cancer detection behaviors, processes and technologies that would result in more accurate, cost effective, and and/or less intrusive screening methods that detect cancer significantly earlier.

*Strategies:*

1. Support basic behavioral research on the role of culture in efforts to improve screening utilization and follow-up of screening abnormalities to add to the knowledge base that informs behavior change interventions among culturally diverse communities.
2. Use state funding for increased research on detection technology related to screening, including breast cancer screening for pre-menopausal women.
3. Use state funding for increased research on social and behavioral factors related to screening.
4. Develop and implement mechanisms to regularly disseminate and translate results of social/behavioral research into community-based programs.
5. Design, implement, fund and evaluate breast and cervical cancer early-detection demonstration projects in collaboration with community-based organizations, medical schools, and research centers.
6. Coordinate with other research efforts nationwide to learn from their efforts and avoid duplication.
7. Review reimbursement rates and ensure that the cost of new technologies and techniques are adequately covered by all payors once they have been accepted as the standard of care.
8. Adapt regulations to the new technologic capabilities to employ these technologies as they become accepted as the standard of care.
9. Influence and support organizational policies and legislation that enhance a woman's ability to obtain cancer screening services, such as payor coverage of cancer screening and diagnostic services, paid time off to obtain a mammogram, and clinics operating during evenings and weekends.

## TREATMENT



*...the inability to cure cancer, and dissatisfaction with survival rates and quality of life from current therapies, is driving the development of new methods.*

The sociopolitical and the medical climate surrounding breast and cervical cancer has changed markedly over the last several decades. Women diagnosed with these cancers today have many more treatment options than before. In many cases, breast-conserving therapies have proven as effective as radical surgery. New cancer therapies have improved survival rates. However, the inability to cure cancer, and dissatisfaction with survival rates and quality of life from current therapies, is driving the development of new methods. A secondary focus is investigating the efficacy of alternative or complementary therapies.

There are many—and often confusing—terms associated with unconventional therapies: adjunctive, alternative, complementary, unorthodox and unconventional. The best of these diverse groups of interventions, which are widely used but have not been studied, or have been ignored by mainstream western medicine,<sup>59</sup> are generally those that many patients believe enhance quality of life, promote general health and engage the patient in her own treatment in psychologically and sometimes physically beneficial ways.<sup>60</sup> They may include massage therapy, yoga, and meditation to reduce stress (referred to as supportive care in the past).<sup>61</sup> Integrative medicine, a relatively new area, brings together alternative and traditional care in one clinical setting where practitioners of both modalities work as a team, often under one roof. Californians are especially drawn to alternative therapies: according to a Los Angeles Times survey, Californians are twice as likely as other Americans to try treatments like chiropractic, acupuncture or homeopathy.<sup>62</sup>

Because the Treatment Committee believed strongly that effective and appropriate follow-up and support for people with cancer and for their families improves the ability of patients to cope with their illness (and to do so in relative comfort), many of the recommended strategies in this section were framed with "state-of-the-art" treatment and quality of life in mind. The highest ranked concern of this Committee, as indeed of the majority of others who contributed to this Plan, was the lack of funding for treating breast and cervical cancer. Toward that end, the Committee made provision for creating a permanent funding source for subsidized breast and cervical cancer treatment services one of its recommended strategies.

Shared decision-making and greater patient involvement in breast and cervical cancer care are now encouraged, and a wealth of consumer information and resources are available in both print and online to assist women in making these choices. The Committee recommended strategies under several objectives for improving these materials and resources by tailoring them to better fit the needs of the state's diverse populations.

## TREATMENT

### GOALS AND OBJECTIVES

#### GOAL 1

Better define quality of care for cancer treatment.

##### ***Objective 1. Improve and Expand Data Reporting***

To improve and expand the standardized collection, analysis and reporting of breast and cervical cancer data.

*Strategies:*

1. Require complete collection and reporting of additional data elements to the California Cancer Registry, such as diagnosis and primary and recurrent inpatient and outpatient treatment, including but not limited to radiation therapy, chemotherapy regimen, site of care, and provider type.
2. Convene an expert group, including a cohort of women identified through rapid case ascertainment, to review existing tools, such as the Institute of Medicine's *Ensuring Quality of Care*, that measure patient satisfaction and quality of life and recommend a standardized means to collect and report these data to the California Cancer Registry.

##### ***Objective 2. Knowledge of Treatment Options***

To increase knowledge of health care providers and the general public about effective treatment, including ways to maximize quality of life, for breast and cervical cancer for all stages of disease, including recurrence.

*Strategies:*

1. Support efforts by groups such as the National Commission on Quality Assurance (NCQA) to ensure provider compliance in distributing the DHS booklet *A Woman's Guide to Breast Cancer Diagnosis and Treatment*.
2. Introduce legislation that requires the State to develop, disseminate and review every three years or when necessary a patient booklet on cervical cancer treatment options in multiple languages that providers are required to give to women who are newly diagnosed with cervical cancer, similar to the DHS booklet for breast cancer.
3. Publicize websites, such as the National Cancer Institute's (NCI), and create and maintain a California-specific website for providers and the general public that links to resources providing information about breast and cervical cancer.
4. Sponsor statewide symposia and continuing education programs on treatments and updates that focus on maximizing quality of life.

**Better define quality of care for cancer treatment.**



**Increase access to state-of-the-art treatment for breast and cervical cancer based on scientific evidence.**

### ***Objective 3. Improved Outcomes***

To hold health care providers accountable for improved treatment outcomes.

#### *Strategies:*

1. Convene an expert panel that includes consumers to establish standardized quality goals and outcome measures.
2. Establish HEDIS and other measures for breast and cervical cancer, and collect and report outcome data related to specific treatment modalities by stage, such as the proportion of women undergoing lumpectomy versus mastectomy, and the proportion undergoing combined cervical cancer therapy.

### ***Objective 4. Quality of Life***

To optimize the quality of life for people living with breast and cervical cancer.

#### *Strategies:*

1. Support additional research about the influence of various factors on survivors' quality of life, such as family support, spirituality, sexuality, finances, education, nutrition and physical activity.
2. Develop or improve models of case management that encompass the physical, social, emotional/spiritual, and financial impacts on a person's life that could be adapted for use in a variety of health care settings and systems.

## ***GOAL 2***

Increase access to state-of-the-art treatment for breast and cervical cancer based on scientific evidence.

### ***Objective 1. Barriers***

To reduce or eliminate financial, age and racial/ethnic discrimination, and other barriers to breast and cervical cancer treatment services.

#### *Strategies:*

1. Establish through legislation a permanent government-funded system that covers 100% of the estimated need for the treatment of breast and cervical cancer for the uninsured and underinsured.
2. Develop and maintain a county-by-county directory of cancer treatment and community support resources, such as transportation, practical support services, and free or low-cost childcare and elder care that could be managed and disseminated by the Breast Cancer Partnerships and other advocacy groups.

## TREATMENT

### ***Objective 2. Models of Care***

To evaluate existing models of care and identify best practices.

#### *Strategies:*

1. Convene a statewide, multidisciplinary group composed of health care providers treating breast and cervical cancer and consumers working on health issues related to the two diseases to evaluate models and best practices in partnership with national groups doing similar efforts.
2. Support increased research, including clinical trials, about emerging technologies, such as gene therapy, and disseminate findings.
3. Support research into improved models of care and support pilot and demonstration projects that apply these research findings.

### ***Objective 3. Coordination and Collaboration***

To improve coordination and collaboration among health care providers for patient care and treatment, including the provision of community support services.

#### *Strategies:*

1. Provide information about the existence of and eligibility for clinical trials to health care providers treating breast and cervical cancer and to private and public agencies through a quarterly newsletter and other materials via Internet and in print.
2. Review existing and create a standardized definition for patient navigators/advocates who assist women to maneuver through health care systems, and establish coverage for the cost of these services by all payor sources.
3. Coordinate legislative and regulatory efforts that are designed to reduce financial and other barriers to multispecialty care.
4. Establish and use tracking systems monitored by accrediting and credentialing organizations, such as the Joint Commission on Accreditation of Health Organizations and NCQA, that would require documentation of offering women the full spectrum of multispecialty care for their treatment.

### ***Objective 4. Clinical Trials***

To increase participation in clinical trials by diverse groups of women.

#### *Strategies:*

1. Remove barriers and offer educational programs for women in diverse communities that increase their understanding of the value and potential benefits and risks of participation in clinical trials.
2. Fund additional research on treatment outcomes that is culturally specific and includes the cost of participation, such as transportation, child care, and time lost from work, and disseminate findings as appropriate.
3. Support more community-based efforts that use peers and other advocates to educate and keep women informed about cancer treatment, clinical trials, and outcomes of current treatment regimens.

**Objective 5. Information Systems**

To increase the number of health care providers who adopt management information systems to track patient progress after diagnosis of breast and/or cervical cancer and cervical dysplasia to assure that appropriate and timely treatment is provided.

*Strategies:*

1. Review existing or develop guidelines and standards for the expectations of information systems, such as timeliness and appropriateness of care.
2. Work with vendors to incorporate these standards and guidelines into electronic and other management information systems.
3. Establish various incentives for providers such as tax breaks, rebates, small business loans for purchase of information systems, and technical support.

**Objective 6. Provider Linkages**

To increase efforts to establish linkages among geographically separated\* providers so that optimal treatment is more accessible to all breast and cervical cancer patients.

*Strategies:*

1. Promote the use of telemedicine and other electronic means of information sharing and patient consultation for treatment and follow up.
2. Promote Oncology Nurse Certification and Oncology Nursing Society membership to increase the number of nurses in California with the ability to share specialized information, particularly in rural areas.
3. Create and promote opportunities for isolated providers to participate in cancer center grand rounds and other clinical settings that can forge relationships for referral and consultation purposes, enhance their knowledge about specialty cancer care, and delineate their role as part of a multidisciplinary team in providing treatment services.

**Objective 7. Complementary Approaches\*\***

To increase knowledge about the use, possible benefits and risks of complementary approaches in breast and cervical cancer.

*Strategies:*

1. Support more research, including clinical trials, to evaluate the use and efficacy of complementary approaches to treatment, and disseminate findings from new and existing research through professional and lay educational symposia and electronic and print media that reach culturally diverse populations.
2. Support and evaluate translational activities that apply complementary research findings to community and provider settings.

\*Includes rural/urban separation, between-provider separation within rural areas, and between-provider separation within urban/inner city areas.

\*\*Supportive approaches that complement conventional (mainstream) therapy, are intrinsically health-promoting and may help control symptoms and improve well-being. Examples might include meditation to reduce stress, peppermint tea for nausea, and acupuncture for chronic back pain. (American Cancer Society)

## TREATMENT

3. Establish a linkage with the National Center for Complementary and Alternative Medicine at the National Institutes of Health and support increased funding for this Center.

### GOAL 3

Advance public policy to improve breast and cervical cancer treatment and access to treatment.

#### *Objective 1. Public Policy*

To develop and implement a coordinated public policy agenda among constituencies and lawmakers to improve the financing, access and delivery of quality breast and cervical cancer treatment.

#### *Strategies:*

1. Establish through legislation a permanent government-funded system that covers 100% of the estimated need for the treatment of breast and cervical cancer for the uninsured and underinsured.
2. Support an independent study of the costs of breast and cervical cancer treatment in public and private cancer treatment systems to provide a basis for State funding.
3. Convene a statewide, multidisciplinary group working on issues related to breast and cervical cancer to develop and implement a coordinated public policy agenda in partnership with state and national groups undertaking similar efforts.
4. Conduct annual informational briefings about breast and cervical cancer treatment, such as forums and town hall meetings, for policymakers, media and the public in conjunction with the medical and advocacy community.
5. Prepare and distribute fact sheets and executive summaries on breast and cervical cancer treatment for policymakers and their staff.

**Advance public policy to improve breast and cervical cancer treatment and access to treatment.**

The next phase of the strategic planning process is to develop a roll-out plan for promoting, implementing, and tracking the progress of the Plan activities, with leadership and coordination being carried out with the assistance of the California Breast and Cervical Cancer Advisory Council. To initiate the process, the Cancer Detection Section of DHS will assure that information about key organizations and groups that need to be involved is gathered, their current efforts are described, and their interest in helping to advance strategies in the Plan determined. An initial listing of some of the key statewide resources and organizations that were identified during the Plan development process is found in Appendix B.

Because statewide mobilization of voluntary, private, and public sector cancer-related organizations in California is required to implement the Plan over the next five years, the Plan will be promoted statewide and commitment of additional strategic partners will be solicited. It is anticipated that specific organizations will choose to work on the strategies that are the most compatible with their mission, business objectives, capacities and resources. As groups commit their involvement, specific action steps to implement the strategies, as well as an evaluation plan for measuring their impact, will be developed.

Effective collaboration and coordination will require some, if not all, of the following:

- Establishing a Coordinating Committee for implementation.
- Developing specific detailed operational plans to implement various aspects of the Plan in California's diverse regions, communities, and sectors.
- Holding a statewide convocation of community leaders to control breast and cervical cancer.
- Conducting a statewide media and publicity campaign(s) to raise awareness about the Plan and the opportunities it presents.
- Encouraging concerned organizations and groups to establish internal committees or task forces on breast and cervical cancer prevention and control.
- Establishing an on-line database of California's resources, policies, projects, programs, materials, and statistics on breast and cervical cancer prevention and control.
- Developing a training plan.
- Developing a management plan, structure and resources.

## EVALUATION

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Without specifying outcome measures and periodic monitoring and documentation, the effectiveness of the Plan will be unknown, public and private resources may be less than wisely utilized, and the optimal development of future Plans may be impeded.

A monitoring and tracking system must be developed to evaluate whether, how, and where each of the identified strategies is being implemented. The evaluation needs to cover three areas. The evaluation will assess the degree to which each strategy has been implemented or is completed (process); the evaluation will include an assessment of behaviors, knowledge, and access to care that would be expected to change as a result of the implementation of the strategies in this Plan (impact); and, the evaluation will assess the degree to which a reduction in the incidence of breast and cervical cancer or down-staging of these cancers has occurred (outcome) compared to baseline data from the year 1998.

The availability of adequate evaluative information is important for the effective implementation of this Plan. Some of the necessary data are currently collected by California agencies, while some are not. Provision for filling some of these gaps has been made in the recommended strategies, and if implemented within the next five years will help to identify needs and target resources more appropriately. These data and information issues will be reviewed during the five-year span of this Plan as part of the ongoing evaluation process.

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## APPENDICES

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Early efforts by the California Department of Health Services (DHS) to undertake a planning process for breast and cervical cancer control laid the groundwork for the present five-year Breast and Cervical Cancer Plan for California. The Plan is a product of a Plan Task Force, specially convened by DHS in early 1999, and charged with developing a statewide, comprehensive cancer control Plan for breast and cervical cancer in California. The Plan planning process was endorsed by the Department's Breast and Cervical Cancer Advisory Council at its October 1998 meeting.

This Plan is the result of a long-standing desire by many advocates, policymakers, providers, survivors, researchers and other stakeholders to focus attention on the unacceptable rate of breast and cervical cancer among California women, and to identify a common and strategic direction for channeling resources to reduce breast and cervical cancer in California in the next half-decade. Although the planning process was convened by DHS, many individuals and organizations, described below, provided input and participated in its development, and endorse its product.

To facilitate the planning process, the DHS Cancer Detection Section (CDS) used its interagency agreement relationship to contract with the California State University Institute (CSUI). CSUI solicited proposals through a competitive process, and selected California Elected Women's Association for Education and Research (CEWAER) to develop the Plan. CEWAER hired Barbara M. Aved, Ph.D. as the consultant to conduct the research, facilitate the planning process, and produce the Plan.

### **Intended Audiences for the Plan**

This Plan is intended for the four audiences who can most impact breast and cervical cancer control in California through policy and/or service delivery:

- Policymakers
- Voluntary and community-based organizations and advocates
- Health care providers and delivery systems
- Research entities

Every level of government in California impacts cancer control policy. At the highest level of government, the governor, state legislators, and the judicial system can develop and enforce policies that will reduce the rates of disease and death due to breast and cervical cancer. Data collection by state agencies, such as DHS, California Cancer Registry, the Office of Statewide Health Planning and Development, and Department of Education, can help to assess cancer policy needs in California. These agencies also implement programs and provide services to support existing policies. At the local level of government, counties can promote breast and cervical cancer education and awareness activities, promote healthy environments and lifestyles, and identify and link high-risk and difficult-to-engage women with needed screening and treatment services. At the broadest level of government, the citizens of California can advocate for improved cancer control information, data collection, policies and access to services.

In conjunction with policy and education, cancer control is achieved through the services offered by health care providers. Services are provided along a cancer control continuum of risk reduction/prevention, screening, and treatment. Health care providers offer these services in a variety of combinations and settings in hospitals, clinics, health maintenance organizations, community-based organizations, and schools. Administrators, program planners, and researchers make decisions that impact the types of cancer services available in California. Non-profit organizations, as well as cancer survivor organizations, offer services, referrals to services, and networking opportunities for those involved with cancer control and to the patient community. This Plan refers to these individuals and groups involved with breast and cervical cancer control as stakeholders.

### **Acknowledgments**

The process of developing the Plan has drawn together many individuals and organizations to examine the needs related to breast and cervical cancer prevention, early detection, and treatment. Collectively, they provided an understanding of breast and cervical cancer issues, and a rich comprehension of the challenge as it affects Californians. This Plan would not have been possible without the extraordinary generosity of the many individuals, organizations, consultants, and scientific experts who have assisted in various ways in its development.

#### ***The Breast and Cervical Cancer Plan Task Force***

The creation of the Task Force was the result of a joint agreement between DHS and its Breast and Cervical Cancer Advisory Council. Members of both groups believed that the process—as well as the product—would be fundamentally enhanced by creating an independent body whose sole purpose was to undertake such a strategic Plan. The Council elected to play an advisory role, and several of its members served as expert reviewers and Task Force members. A list of the 34 individuals who served on the Task Force, and the organizations they are drawn from, is included as Attachment C in the Appendices.

#### ***Other Expert Reviewers***

Individuals representing special areas of expertise who could not spare the time to participate in the many Task Force Committee meetings volunteered to review one or more drafts of the Plan. These individuals represented radiologists, pathologists, and medical and surgical oncologists, and are listed in Appendix D. We are grateful to them for sharing their expertise and thoughtful comments.

#### ***California Breast and Cervical Cancer Advisory Council***

Appointed by the Director of DHS, the Advisory Council has members representing various constituencies within the breast and cervical cancer community as legislatively specified. Members include representatives of voluntary agencies, professional organizations, academia, health care practitioners, and cancer survivors. A list of the members is included as Appendix E. In addition to individual members of the Council serving on the Plan Task Force, the Advisory Council reviewed and provided feedback on the Plan during its development.

***Cancer Detection Section***

The mission of the Cancer Detection Section (CDS) is to detect early those types of cancer, their preceding cellular changes or risks for which early detection, coupled with timely entry into appropriate care, reduces mortality and sustains quality of life. Current CDS programs and resources focus on reducing mortality from breast and cervical cancer among low-income, uninsured and underinsured women. CDS is located within DHS in the Cancer Control Branch of the Chronic Disease and Injury Control Division. CDS spearheaded the Plan development process and provided expert guidance throughout the project.

***Plan Contractors and Consultants***

California State University Institute (CSUI) was established in 1993 to enhance the support of the CSU system and its 22 campuses. Using innovative alliances and public/private partnerships, CSUI strives to support both the academic and community service missions of the CSU by leveraging the faculty, staff and facilities of the CSU. CSUI has provided both program and administrative support to the DHS BCEDP since 1997. CSUI served a key role in the planning, organization and management of this Plan development project.

CEWAER, the California Elected Women's Association for Education and Research, is the nation's oldest and largest association of elected women officials, and was the CSUI subcontractor for this project. Founded in 1974, its goals are to support women serving in elected or appointed office, and to stimulate education and research on public policy issues as they relate to women, families and children. CEWAER sponsors workshops, seminars and training programs throughout the state, and has produced policy papers and fact sheets on such topics as women's physical, mental, occupational and reproductive health, health care reform, breast cancer, violence against women, older women's health, and foster care. CEWAER hosted all of the Task Force meetings, conducted two public forums to inform the Plan development process, and helped edit the final Plan.

BARBARA AVED ASSOCIATES (BAA), a Sacramento-based health consulting firm established in 1986, served as CEWAER's consultant for the project. The firm specializes in public health and public policy, and provides strategic and business planning, program development, and evaluation for public and private sector agencies, foundations, and professional associations and provider groups. Dr. Aved, a specialist in women's health, conducted the background research and facilitated the planning process, convened the Task Force Committees, and prepared the Plan.

***Plan Development Management Team***

A team consisting of staff from CDS, CSUI, CEWAER and the consultant oversaw and managed the planning process. The team met frequently throughout the project (October 1998 – January 2000), sometimes bi-weekly during the early months. The team reviewed findings from all of the information-gathering activities and helped make decisions about various aspects of the project. Three CDS staff served as liaisons to the Plan Task Force Committees to answer questions, clarify policies, and provide additional data and information. The team members are listed in Appendix F.

## Background Research

### *Key Informant Interviews*

One of the most important parts of the information-gathering phase of the planning process was talking with experts to solicit their ideas and opinions. About 25 individuals from throughout the state representing advocacy, policymaking, research, health delivery systems, and medical providers were identified by CDS and interviewed by the consultant. A list of these individuals is included as Appendix G.

We asked questions ranging from priorities the Plan should address, to recommendations for strategies, to suggestions for soliciting buy-in from stakeholder organizations. Findings from the key informant interviews were shared with the Task Force, and formed an important part of the framework for the Plan. For example, the majority of interviewees ranked finding a long-term solution for treatment funds and improving access to services for the highest-risk populations as the highest priorities. They also suggested the Plan cover at least, but no more than, a five-year period, have a statewide focus, and identify objectives that were achievable in the time span.

Two additional groups were queried and their views incorporated within the Plan development process. A CDS-designed survey, similar to the key informant interview questionnaire, was sent to members of the State Breast and Cervical Cancer Advisory Council and their feedback was summarized by the consultant. The consultant interviewed 18 DHS staff, most of whom worked in CDS or related cancer control activities, and their feedback provided a rich base of understanding for some of the key issues, data, and current state-supported activities for breast and cervical cancer found in this Plan.

### *Review of Other States' Plans*

It was very helpful to examine how a number of other states approached cancer control planning for breast and cervical cancer. The Task Force and consultant reviewed the following states' Plans (most of which were for comprehensive cancer control, not solely breast and cervical cancer control), and wish to express appreciation to them for the ideas and learning they provided to the California Planning process. Our Plan is richer for their insights and experience.

- Colorado
- Hawaii
- Maryland
- Massachusetts
- Michigan
- New Mexico
- North Carolina
- Texas



### ***Consumer and Provider Focus Groups***

As a part of the CSUI contract, Dr. Relda Robertson-Beckley organized a number of focus groups throughout the state with consumers and providers to supplement the information gathering process. A summary of findings from these sessions was shared with the Task Force in the development of this Plan and is included as Appendix H.

Forty-two women, matching the diverse characteristics of the state's target group, participated in focus groups, and responded to questions ranging from their experiences seeking breast and cervical cancer education, screening, and treatment services in their communities to ideas about strategies for improving such services. The consumers identified many barriers to receiving cancer-related services, including "self-neglect" (their own term), lack of health insurance, language difficulties, cultural and religious beliefs, and transportation problems. A number of the women perceived that their physicians had very little time to explain breast self-exam, diagnoses, treatment, and general health promotion. They indicated a desire for more information, particularly through culturally specific materials, about health education and healthy lifestyle.

Twenty-one providers, including physicians, nurses, and health educators, attended one of several breakfast meetings to participate in a focus group session. The providers identified several issues that impacted their ability to provide services and reach needy populations. These issues included the lack of time for talking with and teaching clients, the abundance of paperwork required to process billing, and inadequate reimbursement rates. The lack of treatment funds for breast and cervical cancer was identified as a major gap that needed to be addressed.

### ***Public Forums***

In April 1999, CEWAER hosted a Women's Health Symposium focused on breast and cervical cancer in San Diego. An expert panel, which was comprised of representatives of the medical community, researchers, advocates, legislators, and cancer survivors, presented highlights of current knowledge and issues related to risk reduction, detection and treatment, and answered many questions from the audience. Attendees, who included the general public, were asked what they would like to see in a state Plan for Breast and Cervical Cancer. A second symposium for the same purpose was held in Sacramento in September 1999. Over 500 people attended these symposia and provided valuable insight about research and service needs for breast and cervical cancer. A summary of findings from the symposia is included as Appendix I.

### ***The Committee Structures***

Various alternatives for developing the Plan – from working with existing groups to forming a new one – were considered, and CDS elected to create a new ad hoc Task Force that drew together existing groups, such as the Breast Cancer Partnerships, organizations concerned with cancer control, health care delivery,

## BACKGROUND OF THE PLAN

advocacy, and advisory bodies involved in breast and cervical cancer. Criteria for selection of members included representation of the diversity of populations in California, area(s) of expertise, and organizational representation. A letter of invitation co-signed by CDS, the Advisory Council, and CEWAER that explained the purpose of the Plan and the anticipated time commitment was sent to prospective members and 34 individuals accepted.

One of the working assumptions of the project was that the majority of the Plan development would be done at the committee level. Consequently, the project team considered three options for organizing the Task Force: a) by target population (e.g., physicians, patients); b) by strategy (e.g., education, quality improvement); and, c) by the continuum of cancer (i.e., risk reduction/prevention, detection, treatment). We saw evidence of the use of all three of these approaches in other states' cancer Plans. It was recognized, however, that no matter which way the committees were structured and the work organized, there would ultimately be cross-over among all areas and that there were probably no significant advantages or disadvantages to any of the approaches. Thus, the organizational structure used was the creation of three Committees, Risk Reduction/Prevention, Detection, and Treatment, with Task Force members assigned to each according to preference, when possible, and area of expertise. (The list of Task Force members in the appendices identifies the Committee on which each member served.)

Task Force and Committee meetings were held in different parts of the state to provide an opportunity for others to attend. There was an attempt to balance the Committee assignments by geographical location to spread the burden of travel to meetings equitably, but this did not always happen. The consultant facilitated the Committee meetings, and Geoff Ball, Ph.D., facilitated the Task Force meetings.

The objectives and strategies in the Plan were developed by the individual Committees as a group over the course of several meetings, and reviewed by the Task Force as a whole. Feedback from Task Force members was considered at the Committee level and incorporated into the Plan. To broaden the opportunity to provide comments, a draft of the Plan was posted on the CEWAER website, and also widely disseminated through statewide mailing lists of cancer-related organizations.

The following is a selected sample of organizations that represent statewide sources of data and research, programs, and resources that were identified during the Plan development process.

### ***California Cancer Registry***

Legislation creating the California Cancer Registry (CCR) was passed in 1985 in response to concerns in the community about a perceived increase in cancer. Statewide collection of information on incident cancers was implemented in 1988 under the Statewide Cancer Reporting Law. The CCR is a partnership between the California Department of Health Services, the California Public Health Foundation, and ten regional cancer registries.

The state cancer surveillance system uses CCR data to monitor cancer trends and risk over time by geographic region, age, sex, race/ethnicity, and other characteristics of the California population. Since 1991, the CCR has published annual reports with detailed information on the risk of developing and dying from cancer in California. Five percent of the cigarette tax revenue generated by the 1993 legislation that created the Breast Cancer Fund has been allocated to support CCR surveillance activities.

### ***Breast Cancer Research Program***

The California Breast Cancer Research Program (BCRP) was established at the University of California, Office of the President, in 1993. Funded by a portion of the 2-cent cigarette tax imposed by the Breast Cancer Act of 1993, the Program spearheads efforts to stimulate and fund innovative and creative breast cancer research. Each year, this tax provides approximately \$17 million devoted exclusively to research on the causes, prevention, detection, treatment and cure of breast cancer. Additional funds come from taxpayer donations selected on the state income tax return, and from private donations. The Program has invested more than \$75 million in breast cancer research since 1994.

The mission of the California Breast Cancer Research Program is to reduce the impact of breast cancer in California by supporting research on breast cancer and facilitating the dissemination of research findings and their translation into public health practice. The Breast Cancer Research Council, which is an advisory committee to the University, determines the goals and priorities of the research program, establishes program policies, oversees peer review of submitted applications and makes funding recommendations. Review committees composed of expert scientists and breast cancer advocates from outside California are brought together each year to evaluate the scientific merit of applications.

The BCRP funds support research projects and training of both beginning and experienced scientists in breast cancer research. BCRP's funding provides critical leverage in developing new scientific infrastructure and networks crucial for a comprehensive approach to the problem of breast cancer. New program areas in translational and collaborative research, as well as community partnerships, have been developed. The funds that the Program directs to research on the causes, prevention, detection and cure of breast cancer are not just monies spent, but are

## KEY STATEWIDE RESOURCES

investments in the future of Californians. By encouraging and identifying innovative research on breast cancer, and attracting and training some of the most talented and gifted scientists into this area of research, California is making an investment that can pay vital dividends for all Californians.

### *American Cancer Society, California Division*

The American Cancer Society, California Division, is composed of 11 regions and units statewide. ACS provides information about cancer and makes referrals to ACS services, as well as to community resources and others who can help the public, patients, and their families understand cancer. Other major roles of ACS are research programs and education of health professionals (physicians, nurses, social workers, dentists, etc.) to improve knowledge and skills about cancer through conferences, workshops and materials. Advocacy efforts relate to public issue matters with the legislature, grass roots community action, and special programs for the individual at risk and cancer patients.

### *California Department of Health Services, Cancer Detection Section*

The Cancer Detection Section (CDS) is located within DHS in the Cancer Control Branch of the Chronic Disease and Injury Control Division. The mission of the CDS is to detect early those types of cancer, their preceding cellular changes or risks for which early detection, coupled with timely entry into appropriate care, reduces mortality and sustains quality of life. Current CDS programs and resources focus on reducing mortality from breast and cervical cancer among low-income, uninsured and underinsured women. The Section operates the federally funded Breast and Cervical Cancer Control Program (BCCCP) and the state-funded Breast Cancer Early Detection Program (BCEDP). The BCCCP has been funded since 1991 by the Centers for Disease Control and Prevention (CDC) under Public Law 101-354, the Breast and Cervical Cancer Mortality Prevention Act of 1990, and has an annual budget of approximately \$6 million. The BCEDP was implemented as a result of the California Breast Cancer Act of 1993, which called for an additional two-cent per pack tax increase on cigarettes. Half of the fund revenue is allocated to the BCEDP, 45 percent to the University of California for breast cancer research, and five percent to the Cancer Registry for related activities. The BCEDP has been augmented with additional funding from the Proposition 99 Unallocated Account for a budget totaling \$29.8 million in 1999-2000.

As of July 1, 1999, with state general funds appropriated for the one-year period July 1, 1999, through June 30, 2000, the Section also provides funding for treatment of women and men diagnosed with breast cancer. These services are administered through a contract awarded to the California Health Collaborative.

Women in California are eligible for CDS program screening and diagnostic services if they are at or below 200 percent of the federal poverty level, have no other insurance coverage, and meet age criteria. Women are ineligible if they have Medi-Cal or if they are eligible to obtain services through other sources, such as the California Office of Family Planning's state-subsidized program, Family PACT (Planning, Access, Care and Treatment). A chart showing a comparison of the BCEDP/BCCCP features is included in the Appendices as Attachment E.

***Contractors and Providers***

- *Regional Breast Cancer Partnerships*

California's 14 Regional Breast Cancer Partnerships are essential to all aspects of implementation of the state-funded breast cancer programs. Foremost among the Partnership function is the vital role played in terms of outreach to California's diverse populations and coordination of local and regional organizations to reduce the impact of breast cancer. Each Partnership employs clinical staff to provide direct services related to provider recruitment, quality assurance, and patient case management. Partnerships improve provider capacity to effectively screen women through provision of training and technical assistance; by providing on-site monitoring and consultation; by improving clinical systems to increase the proportion of women who follow up on abnormal exam and test results; and, through assisting women diagnosed with breast cancer to get treatment. A list of the Partnership is included as Attachment D in the Appendices.

BCCCP. BCCCP provides cervical and breast cancer screening through contracts with 33 agencies with 155 screening sites on multi-year contracts. Eligibility for program services is determined on site. BCCCP will fund breast and cervical cancer screening services to 20,000-21,000 women during FY 1999/2000.

BCEDP. BCEDP provides services through its network of providers. To participate in BCEDP and bill the program for services, providers must be enrolled in Medi-Cal. Additionally, primary care and mammography providers must attend specific training and sign a provider agreement as a condition of participation. BCEDP will fund screening and diagnostic services to approximately 150,000 women during FY 1999/2000.

***The Cancer Information Service at the Northern California Cancer Center***

The Northern California Cancer Center (NCCC), a nationally recognized leader in community-based research and education, studies cancer causes, trends, prevention, detection and survival through its Epidemiology, Cancer Registry, and Prevention Sciences research programs. Its Cancer Information Service (CIS) is a free public service funded by the National Cancer Institute. This award-winning program is the source for the latest, most accurate cancer information for patients, their families, the general public, and health professionals. The CIS develops partnerships with organizations to reach minority and medically underserved audiences with cancer information, and studies ways to promote healthy behaviors and communicate cancer information effectively. The CIS toll-free telephone number is 1-800-4-CANCER. Since 1995, NCCC has administered an 800 information and referral service (1-800-511-2300) for the Cancer Detection Section. The helpline is supported in both English and Spanish and assists low income women to locate a health care provider in their community who offers CDS screening services.

## KEY STATEWIDE RESOURCES

## Appendix B

***California Medical Review, Inc. (CMRI)***

California Medical Review, Inc., (CMRI) is the federally-funded, non-profit health information and quality improvement organization charged with improving the quality of care for California's 3.9 million Medicare beneficiaries. CMRI collaborates with other national, state, regional, and community groups to implement interventions to promote breast health awareness and increase mammography screening among older women throughout California. CMRI provides a number of free services such as mammography materials, patient advocacy, quality improvement campaigns, quality improvement projects, and Medicare beneficiary resources such as a toll-free, multilingual Helpline, and produces publications and resources on Medicare and health-related issues. Information is available by contacting the Helpline at 1-800-841-1602, or visiting the CMRI Website at [www.cmri-ca.org](http://www.cmri-ca.org).

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Brian Montano, Health Administrator, Los Angeles Partnered for Progress, Breast Cancer Partnership

Rena J. Pasick, Dr.P.H., Director, Prevention Sciences, Northern California Cancer Center



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Janice R. Pemberton, Breast and Cervical Cancer Advisory Council Member

Brenda Solorzano, J.D., Senior Policy Analyst, California Medical Association

## Appendix D

## EXPERT REVIEWERS

The following individuals and organizations were furnished draft copies of the plan document with requests for their expert review. We are grateful for the comments and advice of those who participated.

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Bloomers, Tustin

CABCO Women's Cancer Task Force, San Diego

Los Angeles Breast Care Alliance

Santa Barbara Breast Cancer Institute

Save Ourselves/Y-ME, Sacramento

Y-ME South Bay/Long Beach

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## Appendix F

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California Elected Women's Association for Education and Research

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Ted Fourkas  
Editor

**Key Informant Interviews Conducted  
for the California Breast and Cervical Plan  
November 1998 – January 1999**

		Interview Conducted by:		Write in comments only	Representative Category					
		Consult.	CDS Staff		Council Member Contractor	Advocate	Legis/ Political	Survivor	Volntr/Comm Org/Provider Corporate	Clncl/ Resrch
Name	Affiliation									
Patricia Ganz, MD	UCLA	x								x
Pat Samuelson, MD	Acad of Fam Physicians Sac Urban Indian Hlth Cln	x							x	
Susan Merrill, PhD Jeff Newman, MD Mary Ferous, MD	CMRI (Medicare QI contractor in Calif)	x							x	
Wendell Brenner, MD	Calif Conf of Local Health Officers	x					x		x	
Virginia Ernster, MD	UCSF	x								x
Betty Perry	Older Women's League	x				x		x		
Andrea Martin	Breast Cancer Fund	x				x		x		
Arlene Draper	Calif. Breast CA Organizations	x				x				
Sandra Smoley	Former H&W Secretary	x					x	x	x	x
Diane Fink, MD	ACS	x							x	
Charlotte Newhart	ACOG Exec. Dir		x				x		x	
Diane Carr, RN, BSN NP	SF Public Health Dept				x				x	
Deborah Ortiz	State Senator	x				x			x	

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Name	Affiliation									
Rebecca Wold, MD	Calif. Soc. Of Pathologists	x								x
Susan Davis	Assembly-woman	x					x			
Carolyn Tapp	Women of Breast CA Support Project	x				x		x	x	
Fred Margolin, MD	UCSF Breast Center	x								x
Debra Oto-Kent	Health Education Council	x			x				x	
Renetia Martin	Women's Hlth Collabrtv	x				x			x	
Mary Masland	Pacific Bus Grp on Hlth	x						x		
Sally Brooks, RN	ACS	x				x				
Don Beerline, MD	Expert Pathologist		x		x					x
Lucette DeCorde	Calif. Primary Care Assn		x				x		x	
Sherry Goldman RN, NP	UCLA Breast Center			x	x					x
Gregory Talavera, MD	SDSU Sch of Pub Hlth			x	x					
Larry Wagman, MD	Cty Hope Nat'l Med Cntr			x	x					x
Nancy Walsh	CALPERS	x					x			

## SUMMARY OF PROVIDER & CONSUMER FOCUS GROUPS

## Appendix H

### *Purpose of Focus Groups*

The purpose of the consumer and provider focus groups was to provide input into the breast and cervical cancer control plan. The consumer and provider focus groups identified barriers to prevention, detection and treatment; assisted in the understanding of key issues; and, suggested strategies for addressing key barriers and issues as well as for reaching more women.

### *Methods*

#### **Provider/Consumer Focus Group Description**

A total of (4) provider and (6) consumer groups were conducted in (3) regions: northern, central and southern California. Provider focus group locations included: Alameda, Los Angeles Orange County and Fresno. Consumer focus groups were located in Alameda, Contra Costa, Los Angeles and Sacramento. Specific locations were determined by the recruitment process and partnership participation. Three experienced focus group facilitators conducted 1.5 hour sessions.

#### **Consumer Groups**

Consumer focus groups consisted of consumers of Breast Cancer Early Detection Program (BCEDP) or Breast and Cervical Cancer Control Program (BCCCP) services. focus groups were conducted in the following languages: Vietnamese, Spanish and English. A total of 42 participants were recruited.

#### **Provider Groups**

Providers of BCEDP/BCCCP services who serve diverse groups of women were recruited. A total of 21 providers were recruited for participation.

### *Recruitment Criteria*

#### **Consumers**

A total of 42 low-income residents 40 years of age and older who have participated in BCEDP or BCCCP services. The consumer sample group consisted of the following ethnicities:

9 African American	8 Native American	14 Asian/Pacific Islander
5 Hispanic	3 Caucasian	3 Other

Consumers were paid \$35 to participate in focus groups.

#### **Providers**

Providers of BCEDP/BCCCP services that served diverse (i.e. ethnic, age, rural, urban etc.) groups of women were solicited to participate. Providers included physicians, nurses, mammographers, and health educators. A total of 21 providers participated in provider focus groups. Providers were provided breakfast as an incentive for participating.

Providers identified several issues that impacted their ability to provide services and reach needy populations. The lack of treatment funds for cervical cancer was identified as a major gap that needed to be addressed.



***Too Much Time and Paperwork***

The abundance of paperwork and the time that is required to process billing documents is a major problem for providers. Training and technical assistance was identified as a major need just to stay updated on ever changing billing requirements. As a consequence, providers are always under pressure due to the amount of time spent on paper work.

Providers also identified "lack of time" as a major issue. Some providers felt that they could not allocate enough "teaching" time with patients. When asked what were the reasons for not having enough time, most identified an increasing client census as the number one reason.

***Limited Funds and Female Providers***

Limited reimbursement funds for the services provided are a problem. Participants stated that the current reimbursement rates for an exam range from \$13 to \$14 dollars. This amount is not sufficient for actual services provided. Overhead expenses are not covered.

Too few providers, especially female providers was also identified as an issue. Some providers stated that many providers are not aware of new techniques/methods of conducting exams.

***Identifying Symptoms***

Clients lacked knowledge of symptoms or the need for exams, especially those related to cervical cancer. As a result, many women come in with symptoms that they have had for some time. In addition, many women do not know how to conduct appropriate breast self-examination.

***Culture and Women***

Cultural factors were also identified as major issues. Language, male/spouse role definitions and the emphasis placed on female caregiving were identified as issues that impacted outreach and the provision of services. Women also have a number of fears related to not wanting to find out about potential results and fears related to deportations.

***Strategies for reaching more women include the following:***

- Expand/identify cultural outreach outlets.
- Train more providers.
- Increase the number of providers (especially females).
- Educate client on what to expect.
- Build collaborative leverage services (i.e. public health, primary care and social services).
- Provide (or develop) culturally sensitive media campaign and health education materials.
- Provide transportation vouchers as incentives.

## PROVIDER FOCUS GROUP FINDINGS

**1. *What are the top 4 issues facing providers related to early detection and other services for breast and cervical cancer?***

- a) Many providers identified a general lack of awareness of early detection services.
- b) Need for education on importance of self-examination and mammography.
- c) The need for case managers that can handle the multiple social problems that contribute to poor health outcomes, e.g., transportation, family problems, childcare.
- d) The need to educate clients on nutrition and cancer risk reduction.
- e) The impracticality of combining social services with clinical and medical problems.
- f) Environmental factors such as obesity, poverty, and poor nutrition were seen as issues in breast/cervical cancer incidence.
- g) No treatment fund for cervical cancer.
- h) Limited reimbursement funds.
- i) Lack of funds to serve women under 40.
- j) Lack of provider (physician) referral for mammograms to qualifying women.
- k) Women 40+ not demanding services as much as women under 40.
- l) The enormous amount of paperwork to be filled out for each program.
- m) Lack of physician awareness of breast and cervical programs.

**2. *What barriers impede breast and cervical cancer prevention, detection and/or treatment?***

- a) Women are not prioritizing their health concerns and place the needs of others first.
- b) The barriers relate to the women's care-taking role in the home and family.
- c) Transportation, childcare and language are also barriers.
- d) Fears and preconceptions about screening, treatment and the course of the disease, lack of education, information, and awareness about available services.
- e) Provider barriers included tedious paperwork and the complicated reimbursement procedures.
- f) Clients lack knowledge of symptoms or the need for exams, especially those related to cervical cancer.

## Appendix H

## PROVIDER FOCUS GROUP FINDINGS

- g) Cultural taboos: Asian and Latina women are not used to touching their bodies.
- h) Fear: Patients fear being reported to Immigration and Naturalization Service (INS). Legal Status: Since INS has not issued a clear directive on health care services and potential deportation, many Latina clients fear coming in for screening and treatment.
- i) Cultural factors: Language issues, and several other cultural factors played an important role in service provision. The role of the male spouse influenced whether women came in for screening and treatment.
- j) Women tend to sacrifice the little money available to the family to assure food or health care for the children while neglecting their own health.
- k) Lack of transportation: Many of the women live in rural settings. There is a problem with access to services. Most of the services are located in more urbanized areas.
- l) Mobility of the population: Participants mentioned that their target audience was a very mobile population.

**3. *What strategies would you recommend to address some of these issues or barriers?***

- a) Increase the number of providers.
- b) Offer more flexible hours (late evening appointments and extended office hours).
- c) Radio to advertise screening and treatment services.
- d) More community-based health fairs, language translation, culturally competent staff.
- e) Use culturally specific incentives.
- f) Implement measures that will prevent billing/administrative errors that create patient and provider mistrust.
- g) Provide training on billing.
- h) Use neighborhood networks, flea markets, street networks or others to reach women with information or for tracking purposes. While radio and television may work, the non-traditional outlets may be better for mobile populations.
- i) Where possible, participants noted they take a more personalized approach to informing women about the need for exams.

## PROVIDER FOCUS GROUP FINDINGS

- j) Expand program coverage to women age 40 and older.
- k) Provide more literature, PSA's, give-aways, promotional items and bus posters.
- l) Target churches for outreach.
- m) Reduce paper work.
- n) Offer more opportunities for providers to network and share ideas.

**4. *How could we reach more women with breast and cervical cancer education and screening?***

- a) Target churches, radio, ethnic newspapers, and announcements at sports events.
- b) Use celebrity spokespersons, t-shirts, bumper stickers, shower card reminders and a unique and memorable breast cancer symbol/logo. (The current logo is not definable as a breast cancer logo.)
- c) Provide transportation vouchers.

**5. *Are any of these health education topics provided to your patients during routine health visits: exercise, nutrition, diet and/or the use of alcohol?***

- a) Providers acknowledged giving some information on diet, exercise. However, not much time spent on alcohol use. Some women are encouraged to join a weight loss program, walk, dance and to watch fat intake. Many providers stated that they did not have enough time devoted to educating the client around these issues.
- b) Several providers felt that it is important to educate patients about minimizing risk through early detection and by maintaining health behavior. However, the term prevention is used too loosely and the use of exercise and nutrition should not be promoted as behaviors that will prevent breast/cervical cancer. Rather, prevention is a public health term that is not clinically precise. The language should emphasize terms, such as risk reduction, and detection and self-examination.

**Appendix H****OVERVIEW OF CONSUMER FOCUS GROUP FINDINGS**

Consumers identified many barriers to receiving breast and cervical education, treatment and prevention services. Many were consistent with barriers identified in breast and cervical cancer literature. Self-neglect, lack of health insurance, language, culture, fear, transportation and religious beliefs were identified as major barriers.

Consumers also noted unhappiness in general with their current health plan. They also expressed frustration regarding receiving what they perceived as unnecessary/excessive procedures. Many women felt that there was a lack of culturally specific brochures, ads and radio commercials. Finally, consumers also stated that their physicians had very little time to explain Breast Self-Exam techniques, diagnosis, treatment and provided little health education.

Specific strategies for improving breast and cervical cancer education, treatment and prevention services included the following:

- More culturally specific educational materials.
- More focus groups.
- More community-based breast self-exam workshops in the community.
- Create specific breast clinics once per month.
- Expand access to information by targeting local stores, churches and schools.
- Utilize all forms of media to reach more women.
- More information is needed on health lifestyle issues, wellness care and health education.

Most consumers indicated that there is a lack of information focused on healthy lifestyle issues (nutrition, exercise, and substance abuse). It was also noted that a strong emphasis should be placed on health education, culturally specific materials and interpreters. Finally, consumers noted that more written information is needed for outreach into the infrastructure of communities to target grocery stores, churches, laundromats, hair and nail shops, and schools.

## CONSUMER FOCUS GROUP FINDINGS

## Appendix H

**1. *What have been your experiences seeking breast and cervical education, screening, treatment and prevention services in your community? (What about the experiences of family members or friends.)***

- a) Good. My medical doctor is very concerned about my health.
- b) Poor. Appointments are hard to make due to overcrowding.
- c) Interpreters are not always available.
- d) Four women were not happy with some health insurance.
- e) Breast and cervical information was not given to them and procedures were not explained to them.
- f) Mammograms are painful.

**2. *What barriers are you aware of for yourself, friends or family members that impact receiving breast cancer and cervical education, treatment, and prevention services.***

- a) Too busy. Little time to take care of myself. Neglecting taking care of myself and not making an effort to schedule an appointment.
- b) Did not have health insurance for almost a year.
- c) Language, culture, transportation and lack of multi-lingual educational brochures.
- d) Felt very uncomfortable talking about women's issues.
- e) Lack of culturally sensitive materials that encourage African-American women to seek breast and cervical cancer treatment and prevention services.
- f) Fear/denial.
- g) Other feelings that are barriers include: Religious beliefs; anger/mistrust of the medical field; hopelessness; isolation/lack of support from family and friends.
- h) Lack of utilization of health resources.
- i) Lack of information and/or belief that some information may be intentionally erroneous.
- j) Unnecessary/excessive procedures that add costs to care.
- k) Lack of information on the number of women who have successfully survived breast cancer and its treatment (African American).

**3. *How can breast and cervical cancer education, treatment, and prevention services be improved?***

- a) Need more Vietnamese language brochures and a phone line that provides services in their language.
- b) More focus groups.
- c) More opportunities to practice breast self-exam workshops in the community.
- d) More culturally sensitive educational materials.
- e) Information needs to be available and accessible at local stores/shops within the community.
- f) Small group sessions for information/education.
- g) Use breast cancer survivors to speak about their experiences.
- h) Utilize all forms of media to send out information.
- i) Appointments to see a medical doctor should be easily accessible.

**4. *What other information and/or services related to breast and cervical cancer screening, education and treatment would you like to see in your community? How could we reach more women for breast and cervical cancer education and screening?***

- a) More Vietnamese brochures related to breast health, cervical cancer, early detection, prevention and all other related information.
- b) Word of mouth, the media such as newspaper, magazines and television.
- c) More BECDP information available in Vietnamese languages in churches, temples, Asian markets and English as a Second Language (ESL) classes.

**5. *Are you interested in knowing more about the following topics:***

High blood pressure, lowering cholesterol, weight control, becoming physically active; and healthy eating?

- a) All women responded yes.
- b) Need more information on nutrition, diet, and the effects of diet and food choices on breast and cervical health.

## CONSUMER FOCUS GROUP FINDINGS

## Appendix H

***6. In the last year was any information related to the following topics provided to you by your physician or other health professional: exercise, nutrition and diet or alcohol***

- a) Yes. Abdominal exercises.
- b) County clinics have interpreters so the services provided are better than private offices. At the private medical doctor offices, there were only diagnoses and treatment services.
- c) No wellness care or routine check ups are provided. There is not a focus on explanations or health education because of lack of time and lack of interpreters.
- d) Providers give very limited information on these issues. They suggested that they wanted information on the negative consequences/effects of a lack of exercise (as a kind of motivation to become more active).
- e) The positive benefits of exercise should be elevated to a priority topic for African American women.
- f) More written information is needed.

***7. Personal Experiences Receiving Breast Cancer Exams:***

- a) Several women thought they didn't need to see a medical provider since they were healthy.
- b) Several women had problems with Kaiser and other HMOs. Appointment availability was a major problem. Finding the right doctor is also an issue.
- c) Lack of provider education targeting clients is a problem. Several women indicated the lack of attention focused on educating them about their exams and information in general.
- d) One participant mentioned not receiving her results back after having a mammogram.
- e) Pain is highly associated with having a mammogram.



**8. *Suggestions for Better Care:***

- a) Lack of insurance and finances is a major barrier for several women even though they have breast lumps and vaginal bleeding.
- b) Women without insurance often time felt mistreated.
- c) Increase awareness in general.
- d) Go to schools to talk about health care.
- e) Educate health provider first.
- f) Train/educate health providers to be open to answer patient questions.
- g) Need more programs.
- h) Providers should talk about the "process".
- i) Getting the word out:
  - Health fairs
  - Flyers
  - Word of mouth
  - Supermarkets
  - Banks
  - Day care centers
  - Adult schools
  - Utility bills
  - Laundromats
  - Churches
  - Shopping centers
  - Pharmacies

## CONSUMER AND PROVIDER FOCUS GROUPS

**Consumer Focus Group*****Sample Size: 42******Ethnicity***

African American  
Asian  
Native American  
Caucasian  
Hispanic  
Other

***Age Range***

31-90 years of age

***History of Breast Cancer***

Yes: 9/42 (22%)  
No: 15/42 (35%)  
NR: 18/42 (43%)

***Mammogram in the Last 2 years***

Yes: 30/42 (71%)  
No: 11/42 (28%)  
NR: 1/42 (3%)

**Provider Focus Group*****Sample Size: 21******Age Range Served***

30-69 2/21  
30-70 4/21  
40-49 1/21  
40-59 1/21  
40/70 4/21  
All 4/21  
NR 5

***Gender***

Female 13  
Male: 4  
NR: 4

***Practice Environment***

Rural 1/21  
Urban 11/21  
Rural/Urban 4/21  
NR 5/21

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Cam Doan

## **CEWAER Women's Health Symposia *Breast and Cervical Cancer Care in California***

### **Summary of Meetings and Public Input**

To satisfy grant objectives and membership interest, CEWAER organized two regional area symposia to gather input for the Statewide Plan, to promote dialog about breast and cervical cancer, and to empower women as purchasers and users of health care services. The two events followed similar formats; that is, a panel of six experts representing health care providers, researchers, survivors, advocates, policymakers, and educators were questioned by a skilled moderator and by participants in the audience. The dialog was interactive and open, technical and anecdotal.

#### ***April 29, 1999, San Diego***

Introductory comments by Senator Dede Alpert, 39th District, author of the Mammography Quality Assurance Act, giving California the most stringent regulations in the country.

Moderated by Assemblywoman Susan Davis, 76th District, author of AB12 granting women direct access to their obstetrician/gynecologist without first having to see a primary care doctor.

#### ***Panelists:***

Ernie Bodai, M.D., F.A.C.S., Director of Breast Surgical Services at Kaiser Permanente, Sacramento, and initiator of the U.S. Postal Service Breast Cancer Research Stamp.

Vernal H. Branch, Vice President for the Women's Cancer Task Force Y-ME, member of the Governing Board of the BCEDP, and a breast cancer survivor.

Maria Reyes Mason, M.D., Pathologist, Medical Director and President of Cytonet, and Regional Council Chair of the American Cancer Society for San Diego and Imperial Counties.

Georgia Robins Sadler, M.B.A., Ph.D., Associate Director of Community Outreach for the UCSD Cancer Center, directs a cancer awareness program in the Pacific Asian community, and created a program where African American cosmetologists are trained to provide information on early cancer detection.

JoAnn Thomas, Patient Care Coordinator at BCEDP Scripps and the California Health Collaborative, Breast Cancer Treatment Fund, and patient navigator.

Assemblyman Howard Wayne, 78th District, author of AB40 (vetoed by Governor Wilson, reintroduced in 1999) to establish the Breast Cancer Treatment Program for services for uninsured and underinsured women.

## SUMMARY OF CEWAER'S PUBLIC FORUMS

**Summary of Audience Comments:**

- Focus on environmental pollutants
- Need for educating younger women
- Need corporate support to reduce barriers
- Clinical trials are misunderstood, both doctors and women need more education about benefits and limitations of clinical trials, barriers to participation in trials need to be removed
- Diet is viewed as underresearched, could be significant
- Not enough known about alternative therapies, other resources
- Participation of women from different socioeconomic levels and diverse ethnic groups is needed in clinical trials
- If breast cancer is a leading cause of death among women aged 40-55, then why does the early detection program start with women at age 50?
- Advocate to change guidelines controlling mammograms
- Legislate state and federal monies to provide both screening and treatment

***September 8, 1999, Sacramento***

Introductory Comments by Sacramento City Councilwoman, Lauren Hammond.

Moderated by Former Secretary of Health and Welfare, Sandra Smoley, herself a breast cancer survivor.

***Panelists:***

Ernie Bodai, M.D., F.A.C.S., Director of Breast Surgical Services at Kaiser Permanente, Sacramento, and initiator of the U.S. Postal Service Breast Cancer Research Stamp.

Maxine Broussard-Phillips, a nine-year breast cancer survivor and a nineteen-year thyroid cancer survivor. Broussard-Phillips is a member of the Black Women's Task Force of the BCEDP Health Education Council, a board member of Save Ourselves, and a member of Blacks Against Cancer.

Maria Reyes Mason, M.D., Pathologist, Medical Director and President of Cytonet, and Regional Council Chair of the American Cancer Society for San Diego and Imperial Counties.

Georgia Robins Sadler, M.B.A., Ph.D., Associate Director of Community Outreach for the UCSD Cancer Center, directs a cancer awareness program in the Pacific Asian community, and created a program where African American cosmetologists are trained to provide information on early cancer detection.

Paul Wertlake, M.D., Vice President and Chief Medical Officer of Unilab Corporation, is Board certified in anatomic and clinical pathology as well as cytopathology.

Senator Jackie Speier, District 8, was scheduled to participate but was detained in

Committee in the Legislature. Speier's SB 1154 seeks funding for treatment of women who are diagnosed through the BCEDP.

#### Summary of Audience Comments:

- Appropriate reimbursement for pap smears
- Support training programs for cytotechnologists and attract people to this field
- Modify regulations to match new technologies
- Higher number of cancer deaths among poor, older, and certain ethnic populations
- Target mammography and pap screening to save 145,000 lives by 2015
- Best indicator for compliance in mammography is physician recommendation
- Collaborative process for designing plan goals, objectives, strategies to mobilize the state to control this disease
- Magnetic resonance imaging (MRI) is good test but extremely expensive; PET scan to stage disease more accurately and cut back on amount of surgery performed—only one Positronemission tomography (PET) scanner in Sacramento
- Alarming number of recurrences among women who have undergone lumpectomy and radiation as primary treatment
- Pharmaceuticals are now the number one expense in health care plans, not hospital stays any longer
- Women choose to buy their children shoes instead of having a mammogram done—there is not even a word in sign language for it. While there is much to do technologically to advance the rates of finding cancers early, there is even more we can do socioculturally. Major barriers: transportation, cost, child care/elder care, self-exam, “fronting” (pretending to know it all), misinformation
- Advocate in churches, schools, community, health groups to use the knowledge we already have
- Need for different ethnic populations and age groups in clinical trials to add to scientific data
- Need to educate people that clinical trials are not “guinea pig” but rather at least state-of-the-art treatment, no placebos
- Clinical trials should be reimbursed by health maintenance organizations
- It is not just low-income women who are not being screened; it is also busy women
- Eliminate disparity in treatment, make access to care available to everyone
- It is less expensive for State to pay for early treatment and have a survivor contributing for more years than to wait and only pay for the extreme cases that are dying
- Simplify consent forms for clinical trial participation
- Use media to uncomplicate clinical trial participation through well-written articles, educate media to be better partners with health groups

